MANAGEMENT OF TECHNOLOGY

# MEDICAL INFORMATION SOURCES FOR CANCER PATIENTS: HEALTH CARE PROVIDERS PERSPECTIVE

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Thesis under the direction of Professor David M. Dilts

Majority of Americans are paying moderate or a great deal of attention to medical health news. The ability to clearly determine patients' past and potential medical information sources can help both physicians and patients make more efficient medical decisions, but limited study has been done to identify health care providers' attitude about their patients' use of this data. A survey was implemented at the Vanderbilt Ingram Cancer Center, Nashville, TN. Of the 110 individuals approached, 66 (60%) completed the questionnaires. Almost 90% health care providers expected patients to gather information from human sources, even though the quality of information obtained from some of those sources, particularly friends, relatives and acquaintances was poor (2.68 of 7). Patients were recommended to limit using friends, relatives and acquaintances as sources of information. The quality of information obtained from various sources was consistently rated lower by health care providers than patients. Health care providers felt that certain patient demographics are good predictors for cancer information source preferences.

# MEDICAL INFORMATION SOURCES FOR CANCER PATIENTS: HEALTH CARE PROVIDER'S PERSPECTIVE

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## DEDICATION

To my entire family and Aparna

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# CHAPTER I

## INTRODUCTION

Cancer is a serious human health issue (Junghans et al, 2004), and it is the second leading cause of death in the USA, exceeded only by heart disease (ACS, 2004a). In 2000, 1,220,100 people in the United States were diagnosed with cancer for the first time and 563,100 died of some form of this disease (ACS, 2004b). The diagnosis of cancer gives rise to uncertainty, fear and loss, which can be alleviated by communication and information (Fallowfield et al, 1990). Effective communication and appropriate information offered at the right time (Mills & Davidson, 2002) are known to be key to optimal health outcomes.

Information is seen as crucial for treatment and rehabilitation, by relieving anxiety and promoting a sense of control (Balmer, 2005). Therefore understanding what patients need to know, when during the course of care, and from whom they receive this information becomes vital to ensuring the delivery of quality cancer care.

To date, most studies of patients' information needs have been conducted on cancer patients and their use of various sources to gather health information (Mills & Davidson, 2002). There is no in-depth information about the effects of information on clinical setting and almost no information regarding oncologists' attitude towards their patients' use of such information. Therefore it is important to discover health care provider's perspective of the various sources of medical information used by patients to gather information.

## Thesis Objectives

The objectives of this study are to investigate: 1) health care professionals view of the various sources of information patients use to gather information; 2) health care professionals views of the quality of information gathered by cancer patients from various sources; 3) the sources of information health care professionals recommend patients to utilize ; 4) the expected quality of information from the sources recommended by the health care professionals; 5) health care professionals views on whether patients demographics can be used as a predictor for medical information source preferences; and 6) the views of the patients and health care professionals about the past and future sources of medical information and the quality of information gathered from those sources.

A survey was implemented at Vanderbilt Ingram Cancer Center and Vanderbilt Ingram Cancer Center Affiliate Network (VICCAN) conferences. There were three parts in this survey: Part A investigates the demographic information of the health care professionals. Part B investigates participants' perspective of the medical information sources visited by cancer patients in the past and potential medical information sources in the future. Part C investigates the perceived benefits of information in decision making. Emails were sent prior to the study seeking health care professionals'.

This paper is organized in six sections. This is the first section, which is a brief introduction to the study. The second section examines the theories and concepts of medication information sources, patient demography and the impact of information obtained from various sources on the clinical setting. Hypotheses are developed in this section, based on the review of the literature. The third section develops the measurement instrument to test the hypotheses developed in second section. The hypotheses are investigated using a survey methodology that is

described in detail in the fourth section. The fifth section statistically analyzes the data and discusses the results. The sixth section, the discussion and conclusion section delineates the implications both for practice and research, the potential limitations of the present study and, the directions for future research.

# CHAPTER II

## LITERATURE REVIEW

More than 75% of the Americans are paying moderate or a great deal of attention to medical health news and they are turning more frequently to the Internet to obtain health information (Helft et al, 2003). Although, there is an increasing amount of published information about sources of patient obtained medical information for diseases such as heart failure(Gwadry-Sridhar et al, 2003) and AIDS (Buseh et al, 2002), there are only a limited number of studies investigating the views of cancer patients (Mills and Davidson, 2002).

There have been studies done with cancer patients to identify the sources of patient obtained medical information (POMI) (Kakai et al 2003; Basch et al 2004), the quality of the information obtained (Mills & Davidson, 2002), the future sources of POMI (James et al, 1999), the predictors of the information seeking behavior (Mills & Davidson, 2002) and the effect of POMI on the clinical setting (Helft et al,2003). However, there are little in-depth data about the effect of information obtained from patients in the clinical setting and almost no information regarding US oncologists' attitudes about their patients' use of this data (Helft et al, 2003). The ability to clearly determine patients' potential medical information sources can help both physicians and patients make more efficient medical decisions (Dranove 1988; Labelle et al 1994; Kleffens et al 2003; Basch et al, 2004). My study investigates the physicians' views on the POMI sources in order to fill this gap.

This literature review is divided into five sections: 1) importance of information for cancer patients; 2) medical information source preferences; 3) POMI in clinical setting and

physicians' view of the POMI; 4) perceived quality of POMI and 5) predictors of information seeking behavior.

## Importance of information for Cancer Patients

Cancer causes 1 of every 4 death in the USA (ACS, 2004a). Half of all men and one-third of all women in the USA will develop cancer during their lifetimes (ACS, 2004b). The impact of this disease has remained far-reaching. ''You have cancer,'' these words almost always cause devastation in the lives of their recipients (Arora, 2003). Feelings of uncertainty about and loss of control over one's life are common reactions (Mcwilliam et al., 2000). Certainly for the patients themselves, there are profound psychological, physiological, and economic outcomes associated with the diagnosis and treatment of cancer and its symptoms (Ashbury et al., 1998). The diagnosis of cancer is associated with substantial anxiety about prognosis, the availability and effectiveness of treatments and their side effects, and a lack of long-term disease control in many cases (Chen &Sui, 2001). In fact, the anxiety among cancer patients associated with possible death, disfigurement, and disability is often greater than that among patients with other illnesses (Takayamaa et al., 2001).

The diagnosis of cancer gives rise to many fears and misconceptions, and information is vital in building accurate representations of cancer (Sainio & Eriksson, 2003). Cancer is a life-threatening illness and it is crucially important that patients receive honest and adequate information about their condition (Steptoe et al. 1991). Information can play an important role in the successful treatment and rehabilitation of cancer patients (Lauri and Sainio, 1998), particularly because cancer patients today often make a full recovery, or at least live many years with the disease (Thorne, 1999). Also, information can improve the quality of life of a cancer

patient by minimizing the impact of the disease and treatment on patients' functioning and well-being (Arora et al., 2003). The lack of adequate information can have adverse effects such as dissatisfaction, reduction in patient wellbeing and distress in patients and their families (Fallowfield et al, 1990).

Information can help cancer patients to cope with the disease (Steptoe et al. 1991), to control the situation (Hack et al. 1994), to manage the disease and in comforting the patient (Galloway et al. 1997). Lack of information leads to increased uncertainty, anxiety, distress, dissatisfaction and can negatively influence patients treatment decisions (Beaver et al, 1999). Information is crucial to patients when they participate in decision-making concerning their care (Sainio & Eriksson, 2003). Having sufficient information about illness and available treatment options is a necessary precondition for active involvement in treatment decision-making (Pinquart & Duberstein, 2004). To make informed decisions, cancer patients and their families desire information about their diagnosis and prognosis, conventional and alternative therapeutic options, risks and benefits of treatment, and relevant experimental therapies (Chen & Sui, 2001). In general, receiving information about their chance of cure and spread of disease are the patients' top priorities (Pinquart & Duberstein, 2004).

Patients are more aware than they have been in the past about experimental and alternative therapies (Chen & Sui, 2001). More than 75% of Americans reported that they paid a moderate amount or a great deal of attention to medical and health news (Helft et al, 2003). This desire for information is also reflected in the survey conducted by Chen & Sui (2001), with 86.4% of patients reporting that they desired as much information as possible about their illness.

## Medical Information Source Preferences

In their pursuit to gather information, patients refer to various sources of health information (Kakai et al., 2003). Cancer patients consider healthcare providers to be the primary source of such information, especially physicians (Silliman et al., 1998). At the same time, studies have also reported limitations in physicians' information giving behavior that often result in cancer patients leaving the medical visit confused and unsure about several aspects of their disease and its treatment (McWilliam et al 2000; Quirt et al 1997). This is a complex issue, but oncologists in busy clinical practices often have limited time to spend with each patient, and communication may have a lower priority than medical treatment (Chen & Sui, 2001). As a result, patients whose need for information is not satisfied by the healthcare providers turn to other sources of information (Carlsson, 2000). Since information source preferences have a strong impact on patients' decision making, it is important to know where cancer patients go for Patient Obtained Medical Information (POMI) **(**Kleffens et al, 2003**).**

The factors that first enter into people's assessment and choice of information sources are usually tangible, such as whether the source is oral or written, human or virtual, in-house or external, as well as whether lay or authoritative, easily accessible or hard to get at, and whether the source contains information or pointers to information (Hertzum et al, 2002). The choice of information sources can be classified by different types of media, that is, print-based (e.g., books, newspapers, and magazines), broadcast (e.g., radio, TV, and movie), human (e.g., friends, physicians, and patients), and organizations (e.g., NIH and HMO). For today's medical field, information sources not only include traditional media discussed above, but also newer media to facilitate the passage of information (Jefford and Tattersall, 2002; Hertzum et al, 2002). For example, many telephone services (helpline) enable patients to seek emotional support in addition

to specific medical information. With the advancement of information technology, the use of the Internet as a source of health information has been increasing, particularly among cancer patients with higher education and younger age (Elliott & Elliott 2000; Kakai et al 2003). In a study conducted by Pew Research Center in 2003 it was found that 55 million Americans sought health information on the Internet and more than half of patients who actively search for information on the Internet sometimes question their oncologists' advice or recommendations (Helft et al, 2003). The Internet is changing the doctor-patient relationship as it provides patients with the potential to make better health decisions due to ease in access to vast amounts of health information (Sciamannaa et al, 2003).

To summarize, the information gathered from the different sources of POMI helps cancer patients to cope up with disease, manage disease better and get actively involved in medical decision making. The sources of information that have been identified for the purpose of this study have been categorized in Table 1. A complete list of sources with citations has been included in the "Development of the Instrument" chapter.

## POMI in Clinical Setting and Physicians view of POMI

The revolution in health care information has great potential to impact the way that patients interact with their physicians. For example, it is quite likely that 1 hour of Internet searching by an intelligent patient on a reputable website can give the patient information about his or her condition that the physician is not aware of (Ferguson, 2002). When patients attempt to discuss such information with their physicians, most patients (88.3%) found that their physicians were willing to discuss information found in the media or on the Internet, and 67.3% of patients found that their physicians spent a lot (16.4%) or a moderate amount (50.9%) of time discussing this information

**Table 1: Sources Included in Each Source Type**

| | | |
|---|---|---|
| Human Sources | I. | Physician or Physician's Assistant |
| | II. | Nurse or Other Health Professionals |
| | III. | Support Group |
| | IV. | Other Patients |
| | V. | Relatives, Friends and Acquaintances |
| | VI. | Narratives |
| Printed media | I. | Medical Leaflets or Pamphlets |
| | II. | Books |
| | III. | Medical Journals |
| | IV. | Newspapers/ Magazines |
| Networked Sources | I. | Email (Physician, Nurse, Support Group, Patients and other Healthcare Professionals) |
| | II. | Internet or Medical Websites |
| | III. | Telephone or Helpline |
| Organizational sources | I. | Educational Programs by HMO or Hospital |
| | II. | National/Local Medical Information Sources |
| Broadcast media | I. | TV/Radio |
| | II. | Films/Movies |
| Other sources | I. | Audio/ Video Tapes |

with them (Chen & Sui, 2001). However, physicians cannot assume that patients will volunteer all relevant information (Arora, 2003). In fact, cancer patients are reluctant to disclose their psychosocial concerns, and often believe that experience of problems such as depression, fatigue, pain, etc. are inevitable consequences of their disease and its treatment (Bakker et al., 2001). They may feel that there is no point mentioning such issues to the physician as nothing can be done. This avoidance on the part of patients is reinforced by the reluctance of physicians to inquire actively about patients' concerns and feelings (Ford et al., 1996). In an analysis of physicians' knowledge about their patients' preference revealed that physicians did not know their patients' preferences for involvement in making health decisions (Rothenbacher et al. 1997).

Researchers have held deficiencies in physicians' communication (Ford et al. 1996) and interpersonal skills (Arora, 2003) accountable for unsuccessful information exchange between

patients and physicians. Throughout the last 25 years, a number of authors have focused on communication skills in the consultation (Stevensona et al., 2000)**.** The importance of communication skills has long been acknowledged in general practice training (RCGP, 1972), while the need to teach communication skills formally, as part of British undergraduate medical education has also been recognized as an important part of the curriculum (General Medical Council, 1993). Prior to imparting information, physicians have been recommended to actively listen to patients' story without interruption and spent a large proportion of time during visits in information exchange (Simpson et al., 1991).

Yet, despite the advocacy of the use of patient-centered strategies, the data suggests that this does not seem to be happening in practice (Stevensona et al., 2000). For example, on examining physicians' ability to elicit a patient's complete set of concerns found that only 28% of physicians elicited the patient's complete agenda (Frosch & Kaplan, 1999). In all other cases, the patients were "redirected" or "interrupted" before they could finish voicing their concerns, leading to overall fewer patient concerns being spelled out, other concerns arising late in the encounter, and important information not being gathered. Interestingly, while patients in this study were redirected after an average of 23.1 seconds, those patients who were not redirected required an average of only 32 seconds to voice their concerns (Frosch & Kaplan, 1999).

All the above mentioned studies conducted on the communication behavior between patients and physicians suggest that physicians continue to under-estimate both their problems in communicating and their patients' level of distress (McWilliam et al 2000). Even though patients and physicians have been jointly participating more to reach to a decision, physicians do not have a clear understanding of patients' preferences for his or her involvement in the shared decision making, the patients' level of distress or patients concerns and feelings (Rothenbacher et

al. 1997). It could be stated that the successful information exchange is not always taking place between physician and the patient, hence it is possible that physician might not have a clear understanding of patients' knowledge.

Though several studies have examined the quality of medical information and the type of medical information being searched for, little work has been done to evaluate information's possible impact in the clinical setting (Purcell et al 2002; Gagliardi & Jadad 2002; Wilson 2002). There is no information regarding physicians' attitude about their patients' use of medical information (Helft, 2003). My study investigates the physicians' attitude towards the information gathered by patients from different sources. However, from the detailed discussion above, it was determined that it is possible that physicians might not have a clear understanding of patients' knowledge of treatment or of the information gathered by patients from sources of POMI. I therefore hypothesize

*H1: Physicians perception about sources of POMI for cancer patients have used will be different from the sources of POMI patients actually prefer (Patient Past vs. Physician Past).*

The judgments drawn from prior experiences of using various information sources have an impact on the future use of information sources (Hertzum et al., 2002). However, there is no published study asking patients or physicians about the potential sources they will go in future. My colleague Chen Wang, under the guidance of Dr. Dilts is investigating the potential sources of POMI patients will go in the future I will be investigating the sources of POMI physicians recommend their patients to visit in the future. Based on previous discussions I hypothesize that

*H2: Physicians recommendation for the future sources of POMI will be different from cancer patients' preference of the same (Patient Future vs. Physician Future).*

## Quality of POMI

Good decision-making that takes into account medical best-evidence and individual patient factors requires high quality information which includes detailed explanations about the patient's condition, and risks and benefits of different treatment options (Godolphin et al., 2001). Poor reporting of medical information often raise false hopes in patients and their families and results in unrealistic expectations (Chen & Sui, 2001).

As discussed earlier, physicians and other healthcare providers have been the primary source of cancer related information. But, if patients do not get sufficient information from healthcare providers, they rely on other sources to satisfy their need medical information (Chen & Sui, 2001). Unfortunately, much of the information materials available are of poor quality and are often inaccurate or misleading (Solano et al 2003; Coulter 2003). Especially, the advent of Internet has provided a gateway to an abundance of questionable information (Junghans, 2002). With no rules or regulations on the posting of medical and health information on the Internet, the quality of information is quite variable (Chen & Sui, 2001). Therefore, it is important to know patients and physicians view of the quality of information gathered from various information sources.

Some studies have been conducted investigating the quality of information obtained from the preferred sources (Basch et al, 2004; Mills & Davidson, 2002). Among those limited studies, most were done on patients outside US, such as Canada **(**Godolphin et al 2001; Chen & Sui, 2001) Ireland (Mills & Davidson, 2002) and Sweden (Nillson-Ihrfelt et al, 2004). Basch et al's (2004) study was done on cancer patients in US, but it is limited to comparison between electronic and non-electronic sources. There are fewer studies that have asked physicians about the quality of medical information obtained from different sources (Helft et al., 2003; Chen &

Sui, 2001). Moreover, there is no survey that has asked physicians about the quality of information patients obtained by patients from POMI. Therefore it is important for the present study to discover physicians' perspective of the quality of POMI.

In the study of cancer patients and physicians in Canada, Chen & Sui (2001) investigated the views of patients and physicians about the quality of health information available. Most oncologists felt that the media reported accurate medical information only sometimes (60.6%) or rarely (23.8%). However, only 43% patients felt that the media reported accurate medical information. This suggests a difference in the perception of patients and physicians about the quality of health information from the same source. This is the basis for following hypothesis:

*H3: Physicians perception about the quality of POMI used by cancer patients will be different from the patients' view of the same (Patient Past vs. Physician Past).*

Judgments drawn from the prior experiences of using various information sources have an impact on the future use of information sources (Hertzum et al., 2002). However, it is not known if cancer patients will continue going to sources where they believed the quality of information obtained was above average, and will discontinue gathering information from sources where they believed the quality of information obtained was below average. Since there is no study asking patients or physicians about the expected quality of information from the sources they will go in future, Chen Wang, under the guidance of Dr. Dilts is also investigating the quality of information expected from potential sources of POMI patients will go in the future. Also, no study has been conducted on physicians to find out the quality of information expected from the recommended sources of information. My study investigates physicians' view of the expected quality of information from recommended sources and also compares it with patients' view of the expected quality of information from those sources.

*H4: Physicians perception of the expected quality of information from future sources of POMI will be different from cancer patients' perception of the same (Patient Future vs. Physician Future).*

## Predictors of Information Seeking Behavior

Several studies have indicated that there are predictors of information seeking behavior of cancer patients (Blanchard et al, 1988; Derdiarian, 1987). For example, educational background may influence people's health information-seeking behavior in combination with ethnicity (Carlsson, 2000), although all ethnic groups perceive healthcare professionals as the most helpful source of information (Pennbridge et al., 1999)**.** The significant influences of culture on health behaviors due to different set of values, beliefs, attitudes and behaviors of each group have been discussed (Kakai et. al, 2003). Furthermore, research has shown that patients' personality, demographic characteristics and level of knowledge all influence the extent to which professionals decide to give information to their patients (Veronesi et al. 1999). An international survey of women with cancer (n=1932) showed that patients with a higher level of knowledge received more information from staff members than did patients with less knowledge (Veronesi et al. 1999).

Demographics may influence information seeking preference of patients (Mills & Davidson, 2002). The factors pointed out by researchers as the predictors of information seeking and used for the purpose of this study include gender, age, race, education, working status, household income, computer access, insurance coverage and general health condition (Kakai et al 2003; Jefford & Tattersall 2002; Mills & Davidson 2002; Kreps & Kunimoto 1994).

**Table 2: Factors that Influence Cancer Information Seeking**

| Variables | Reference |
|---|---|
| Gender | Carlsson (2000), Mills & Davidson (2002), O'Malley et al (1999) |
| Age | Carlsson (2000), Mills & Davidson (2002), O'Malley et al (1999), Pennbridge et al (1999) |
| Race | Guirdy et al (1998), Kakai et al (2003), O'Malley et al (1999), Ward et al (1993) |
| Education | Carlsson (2000), Guirdy et al (1998), Kakai et al (2003), O'Malley et al (1999), Ward et al (1993) |
| Working status | Kreps & Kunimoto (1994) |
| Household income | Diaz et al (2002), Johnson et al (2001) |
| Computer Access/Use | Basch et al (2004) |
| Insurance Coverage | O'Malley et al (1999) |
| General Health Condition | Fox & Rainee (2000) & Satterlund et al (2003) |

Thus, the ability to clearly determine patients' potential medical information sources preferences can help physician and patients make more efficient and effective joint decisions (Dranove 1988; Labelle et al 1994; Kleffens et al 2003; Basch et al, 2004). However, since physicians dedicate limited time to each patient (Chen & Sui, 2001) and are not always able to develop great rapport and feeling of openness with the patient (Arora, 2003), it is not clear if enough information is transferred from patients to physicians. This is the basis my hypothesis that

*H5: Physicians perception about the predictors of information seeking behavior of cancer patients will be different from the results of analysis of data on patients.*

## Conclusion from the Literature review

Americans are turning more frequently to various sources of health information to gain knowledge about their illness Hence, it is important to understand the effect of patient obtained medical information (POMI) in the clinical setting.

To ensure active involvement and quality outcome physicians should have a clear understanding of patients' knowledge and preferences. Therefore, it is important to understand physicians' view of the sources where patients receive information from, the quality of POMI from those sources, the POMI sources physicians recommend patients, the expected quality of such sources and the impact of patients demographics on information seeking behavior.

An extensive review of the literature indicates that the amount of research done to investigate all of the above mentioned topics is little. Moreover, there has been no study that investigates the sources of information physicians recommend to their patients to obtain medical information and the expected quality of the medical information from those sources. Therefore, research needs to done to investigate the views of physicians about the sources of patient obtained medical information.

# CHAPTER III

# DEVELOPMENT OF THE INSTRUMENT

With the purpose to test the hypothesis developed in the Chapter II, I developed the operational instrument based on the literature review and pretest.

## Instrument from Literature review

From the review of the literature, two major areas: patient obtained medical information (POMI) and the demographics (which act as the predictor of information seeking behavior of patients), which were discussed extensively in the previous chapter were identified for the instrument. Also discussed in the previous chapter was the list of appropriate variables for the purpose of this study for both the major areas. The list of these variables was built with their corresponding references and can be found in the latter part of this chapter.

## Patient Obtained Medical Information Source Variables

Cancer patients consider healthcare providers to be the primary source of such information, especially physicians (Silliman et al., 1998). However, they use wide range of health information to gain knowledge (Cassileth et al 1980; Fallowfield et al 1994).

From the literature review we have included the following variables as the sources of medical information: physician/nurse/healthcare provider, other health professional/consultant, educational program by HMO/hospital, support group, other patients, narratives, relatives/friends/acquaintances, national/local information services, leaflets/pamphlets, medical

journals, books, Internet/medical websites, E-mail, telephone/helpline, TV, radio, newspaper, magazines, audio/video tapes, films and chat-room **(Table 3)**.

## Demographic Variables

Based on the literature review, the variables that we have included are found in table 2, chapter II and include demographic factors influencing the information seeking behavior are as follows: gender, age, race, educational level, working status, household income, computer access, insurance coverage and general health condition

## Table 3: Sources of Patient Obtained Medical Information with Citation.

| | | |
|---|---|---|
| Human Sources | Physician or Physician's Assistant | Cohn et al (2003), Diaz et al (2002), James et al (1999), Kakai et al (2003), Leadbeater (2001), Mills and Davidson (2002), Mossman et al (1999), O'Malley (1999), Pautler et al (2001), Pennbridge et al (1999) |
| | Nurse or Other Health Professionals | Cohn et al (2003), Horrigan et al (2000), Kakai et al (2003), Kleffens et al (2003), Mills and Davidson (2002), Mossman et al (1999), O'Malley (1999), Pautler et al (2001) |
| | Support Group | Cohn et al (2003), Mills and Davidson (2002), Mossman et al (1999) |
| | Other Patients | Carlsson (2000), Johnson et al (2001), Kakai et al (2003), Kleffens et al (2003), Pautler et al (2001) |
| | Relatives, Friends and Acquaintances | Carlsson (2000), Cohn et al (2003), Diaz et al (2002), Johnson et al (2001), Kleffens et al (2003), Leadbeater (2001), McCreadie and Rice (1999), Mills and Davidson (2002),O'Malley (1999), Pautler et al (2001), Pennbridge et al (1999) |
| | Narratives | Carlsson (2000), James et al (1999), Kakai et al (2003), Mills and Davidson (2002) |
| Printed media | Medical Leaflets or Pamphlets | Cohn et al (2003), Gwadry-Sridhar et al (2003), James et al (1999), Kakai et al (2003), O'Malley (1999), Pautler et al (2001) |
| | Books | Carlsson (2000), James et al (1999), McCreadie and Rice (1999), O'Malley (1999), Pennbridge et al (1999) |
| | Medical Journals | Diaz et al (2002), O'Malley (1999) |
| | Newspapers/ Magazines | Carlsson (2000), Cohn et al (2003), Diaz et al (2002), James et al (1999), McCreadie and Rice (1999), O'Malley (1999) |
| Networked Sources | Email (Physician, Nurse, Support Group, Patients and other Healthcare Professionals) | Fox and Fallows (2003), McCreadie and Rice (1999) |
| | Internet or Medical Websites | Carlsson (2000), Cohn et al (2003), Diaz et al (2002), Fox and Fallows (2003), Horrigan et al (2000), James et al (1999), Kakai et al (2003), McCreadie and Rice (1999), Mills and Davidson (2002), Pautler et al (2001), Pennbridge et al (1999) |
| | Telephone or Helpline | Carlsson (2000), Horrigan et al (2000), Kakai et al (2003), Pennbridge et al (1999) |
| Other Sources | Audio/Video Tapes | James et al (1999), McCreadie and Rice (1999), Pautler et al (2001) |
| Broadcast media | TV/Radio | Carlsson (2000), Cohn et al (2003), Diaz et al (2002), James et al (1999), McCreadie and Rice (1999), Mills and Davidson (2002), O'Malley (1999) |
| | Films/Movies | James et al (1999), McCreadie and Rice (1999) |
| Organizational sources | Educational Program by HMO or Hospital | Diaz et al (2002), Pennbridge et al (1999) |
| | National/Local Medical Information Sources | Leadbeater (2001), Mossman et al (1999) |

## Development of Questionnaire & Pre-Test

The questionnaire is divided into five sections: “Letter of Confidentiality”, “Instructions”, Part A “Background Information” and Part B “Medical Information Sources” and Part C “Information Benefits”. The total length of the questionnaire is 6 pages. Two different formats of this version was developed: 1) Paper Based, which can be filled by the participants by hand and 2) Web Based, which can be filled by the participants and returned back to the investigators over the Internet**.**

## Pre-test

The questionnaire developed for the purpose of the study was subjected to two pretests to ensure that participants are able to understand the questions. Feedback was incorporated in the latter versions of the survey.

The first pretest was disturbed to 10 faculty, staff and graduate students. The participants were encouraged by the investigators to identify faults, suggest changes, and write down any doubts or suggestions about all the aspects of the questionnaire including questions, instrument and formats.

The investigator monitored and measured the time needed to answer the questionnaire. The average time to answer the survey was 6 minutes. Several problems related to clarity of the questions were reported by the respondents. The changes recommended in the pretest were incorporated in the third version of the questionnaire.

The second pretest was disturbed to 12 graduate students. The average time to answer the survey remained 6 minutes. Only minor problems were identified and minute change in

formatting was recommended by the participants. The changes recommended in the pretest were incorporated.

# CHAPTER IV

# METHODOLOGY

The survey was implemented at Vanderbilt Ingram Cancer Center and Vanderbilt Ingram Cancer Center Affiliate Network (VICCAN) conferences, which will be explained in detail in the latter part of the chapter. The subject population for this survey was practicing oncologists at the Vanderbilt Ingram Cancer Center and oncologists, research nurses and other care providers at the VICCAN conference. Email was sent to all the oncologists at Vanderbilt Ingram Cancer Center introducing them to the study and requesting for participation. Dr. Dilts is a member of VICCAN and participates in its conferences. The investigators presented the information letter to the members and described to them the purpose of the study. The inclusion criteria for the study were oncologists, research nurses and other active cancer health professionals. There is no risk for the participants to answer the questionnaire. The type of data is mainly quantitative, not linked to specific individuals. There are no identifiers on the survey and none will be collected.

To implement the survey, IRB approval (**IRB# 040295**) was received.

## IRB Approval and Amendment

To conduct this study that involves human subjects, it was mandatory to have an approval from the Vanderbilt University IRB (Institutional Review Board), which is the institution in charge of reviewing proposed human subject research.

## Clinical Setting

Anchored by the Frances Williams Preston Building, Vanderbilt Ingram Cancer Center (VICC) includes the Henry-Joyce Cancer clinic, inpatient units in Vanderbilt Hospital and Children's Hospital, and more than 100 laboratories throughout Vanderbilt University and medical center (VICC facts at a glance, 2003). The VICC is the one of only 38 National Cancer Institute-designated Comprehensive Cancer Center in United States and the only one in Tennessee to earn this highest distinction from the NCI (VICC facts at a glance, 2003). It is ranked among the top 10 cancer care by U.S News world report, and it is the first center to have faculty simultaneously leading three major nation cancer organizations – the American Society for Clinical Oncology, the American Association for Cancer Research and the Association of American Cancer Institutes (VICC facts at a glance, 2003). The VICC has an increasing clinical volume (an average of 7.25 percent each year since 1997) reaching more than 40,000 outpatient visits per year. It has enrolled more than 7,500 patients into clinical trials since 1998, and offers more than 150 clinical trials at any one time for adult and pediatric patients (VICC facts at a glance, 2003). The number of physicians dedicated to treating cancer patients at VICC is approximately 80 (http://www.mc.vanderbilt.edu/vicc/doclist.php). This study was implemented using the oncologists of the Henry – Joyce Cancer Clinic at Vanderbilt.

Additionally, the study was conducted at the conferences held by Vanderbilt Ingram Cancer Center Affiliate Network (VICCAN). The Vanderbilt-Ingram Cancer Center Affiliate Network (VICCAN) was formed in 1994 to provide community oncologists and patients easier access to clinical trials. The network now includes 12 institutions within Tennessee, Kentucky and Georgia. The conferences held by VICCAN are attended by oncologists, nurses, research

administrators and other health professionals. This study was also implemented at a VICCAN conference.

## Pilot Study

With the approval from the IRB and the organizers of VICCAN conference, a pilot test was implemented. The oncologists and other care providers participating in the conference were recruited for the study. A total of 13 cancer care provider were interviewed.

During the survey, the researcher and researcher's assistant introduced themselves to participants, presented the information letter, and described the study. Participants were asked if they were interested in answering the survey. If the nurses agreed to participate, he/she was asked complete the questionnaire. Participants were informed that the information would be kept confidential. After the questionnaire was completed, investigators confirmed that the information collected had no identifying information. Participants were then thanked for their participating in this study.

The feedback from the respondents showed that they thought the questionnaire was clearly stated and comprehensible.

## Full Study

Subjects for the full study were recruited from the Vanderbilt Ingram Cancer Center and VICCAN conference. Email was sent to the oncologists introducing investigators to the participants, presenting the information letter, and describing the study. Oncologists were asked if they are interested in participating. Survey was sent only to those oncologists who gave approval for their participation in the study.

The recruitment at the VICCAN conference was conducted in a similar manner. Email was sent in advance to all the members of the conference introducing investigators to the participants, presenting the information letter, and describing the study. Questionnaires were given only to the interested care providers at the conference.

# CHAPTER V

## RESULTS AND ANALYSIS

This chapter is in two parts; the first deals with a brief description of the sample demographics and the second with hypothesis testing.

All data were coded and entered into a database using SPSS (SPSS for Windows Release 11.01.1; SPSS Inc.). Missing responses, responses that did not fit into one of the specific item responses, and items in which subjects provided more than one response to a survey item were all considered missing. Prior to starting any analysis, data were checked to confirm that there were no data entry errors.

Descriptive statistics are reported as proportions. To compare the demographic characteristics among different health care professionals (oncologists, nurses etc.), Chi-square tests were run for nominal variables (such as gender) and ordinal values (such as age group) (Mills & Davidson, 2002). Due to ordinal nature of the data, Chi- square tests were run to identify the relationship between the demographics of the respondents and the sources of POMI (Mills & Davidson, 2002).

To compare the population mean score for quality of information obtained from different sources of health care professionals and patient, independent sample t-Tests were conducted.

## Sample Demographics

Of the 110 individuals approached, 66 (60%) completed and returned the survey questionnaires. Out of 66 respondents 42 were oncologists, 17 oncology nurses, 2 research nurse and 5 other health care professionals. Demographics for responding subjects are listed in **Table 4**.

The 66 physicians and other health care professionals treated 25 different kinds of cancer, and were divided up into seven different categories of cancer: Breast Cancer, Gastro Intestinal Cancer (G.I.), Head/Neck Cancer, Lung Cancer, Hematological Malignancies and Related Disorders (H.M.), Urinary and Genitourinary Cancers (U.G.), and other cancers such as melanoma and brain cancer. For age and years of practice, we categorized them into six and seven groups respectively for analysis purpose.

From **Table 4,** we can see that there is a well balanced number of respondents from each gender (Male= 51.5%; Female= 48.5%). Other than those, respondents seem to be oncologists (63.6%), between age 31-50 (74.6%), with 6-20 years of experience (64.4%), using Internet to gather medical information (92.4%), mostly practicing in either in urban location (30.3%) or metropolitan area (56.5%) and practicing in medical school (50.0%). The type of cancer respondents frequently treated varied from Head & Neck (4.5%) to Lung (28.8%).

To compare the demographic characteristics among different health care professionals (oncologists, nurses etc.), the Chi square tests (**Table 5**) show that on the whole, there is no significant difference among health care professionals for years of practice, type of cancer frequently treated and use of Internet. But, there are differences in age (P=.014), geographic location of setting (P=.009), type of practice setting (P=.000) and gender (P=.000). The average age of the oncologists was 44.65 years (standard deviation= 7.8 years), 13.2 years of practice (standard deviation= 7.7), 78.6% were males and 69.0% practiced in a metropolitan area. The

average age of the oncologist nurse was 47.2 (standard deviation=9.2), 21.4 years of practice (standard deviation= 9.5), 100% were females and 29.4% practiced in a metropolitan area and 3) the average age of other health care professionals was 36.0 (standard deviation=8.9), 7.8 years of practice (standard deviation= 3.3), 85.7% were females and 42.9% practiced in a metropolitan area.

Chi-square tests also showed that there were no significant differences in demographics between the health care professionals treating different types of cancer **(Table 6)**.

In summary, health care professionals by different types of cancer treated have similar characteristics. However, there are some distinctive demographic characteristics between different health care professionals. The effect of these differences on health care professionals' view of sources of POMI has also been discussed along with hypothesis testing.

## Hypothesis Testing

After completing the sample demographics analysis, data were analyzed to test the hypotheses formulated. Before testing the hypothesis, results from Chen Wang's study on POMI (patients view) was sought. Since the population of this study was health care professionals, results and data from Chen Wang's study was used to compare the outcomes with patients' preference.

Frequency tests were run for all the POMI sources to compare the differences between the views of patients and health care professionals. Z-tests were run to compare and determine if there was a significant difference between the proportions of "yes" between the physicians and patients. T-tests were used for the same purpose when sample size was less than 30 for any item.

## Hypothesis 1

The first hypothesis proposed that health care professionals' perception about sources of POMI for cancer patients have used will be different from the sources of POMI patients prefer.

On the whole, the two most frequently used sources as viewed by both health care professionals and patients were talking with physician or physician's assistant and talking with nurse or other health professionals. There were differences in the views of health professionals and patients on the usage of other sources: 1) healthcare professionals ranked the frequency of talking with other patients, Internet/medical websites, talking with a support group, national/local medical information services, email from relatives/friends/acquaintances, email/chat room with a support group, educational program by HMO/hospital, telephone/helpline, email/chat room with other patients at least one rank higher than compared to the patients 2) healthcare professionals ranked the frequency of talking with relatives/friends/acquaintances, medical leaflets/pamphlets, books, narratives(written stories by other patients), Audio/video tapes, medical journals, films/movies, email from physician or physicians' assistant and email from nurse/other health professionals at least a rank lower than patients and 3) newspapers/magazines and TV/radio were ranked the same by both health care professionals for the frequently used source (**Table 7**).

On average human, networked and organizational sources were ranked higher by healthcare professionals where as printed media and broadcast media were ranked lower by healthcare professionals (**Table 8**).

To further test whether there are significant differences between health care professionals and patients Z-test was run for the comparison between "yes" proportions of physicians and patients. There were significant differences (P=.0000) in the proportion for all the sources except for talking with physicians or physicians' assistant (P=0.4090) (**Table 8**).

Comparison of the analysis for both the groups (physicians and patients) supports the hypothesis 1 for a majority of sources.

## Hypothesis 2

The second hypothesis proposed that health care professionals' recommendation for the future sources of POMI will be different from cancer patients' preference of the same (Patient Future vs. Physician Future).

On the whole, the two frequently used sources as viewed by both health care professionals and patients were talking with physician or physician's assistant and talking with nurse or other health professionals. There were differences in the views of health professionals and patients on the usage of other sources: 1) healthcare professionals ranked the frequency of usage of national/local medical information services, medical leaflets/ pamphlets, talking with a support group, Internet/medical websites, audio/video tapes, email from physician or physicians' assistant, telephone/helpline, email from nurse/other health professionals, email/chat room with a support group, email/chat room with other patients at least one rank higher than compared to the patients, 2) healthcare professionals ranked the frequency of usage of educational program by HMO/hospital, books, talking with other patients, talking with other patients, talking with relatives/friends/acquaintances, newspaper/magazines, narratives(written stories by other patients), TV/radio and email from relatives, friends, acquaintances, films/movies at least one rank lower than the patients and 3) medical journal was ranked the same by both health care professionals for the frequently used source (**Table 9**).

On average networked and organizational were ranked higher by healthcare professionals in comparison with patients views of the frequently visited source of POMI.

Human sources, printed media and broadcast media were ranked lower by health care professionals (**Table 10**).

To further test whether there are significant differences between health care professionals and patients Z-test was run for the comparison between "yes" proportions of physicians and patients. There were significant differences (P=.000) in the proportion for all the sources except for talking with physicians or physicians' assistant (P=.0048), talking with other patients (P=.0030), talking with relatives, friends and acquaintances (P=0.2327), email from relatives/friends/acquaintances (P=.0026), books (P=.0039), TV/radio (P=.0436), newspaper/magazines (P=.3360) and films/movies (P=.0002) (**Table 10**). Comparison of the analysis for both the groups (physicians and patients) support hypothesis 2 for a majority of sources.

## Hypothesis 3

The third hypothesis proposed that health care professional's perception about the quality of POMI used by cancer patients will be different from the patients' view of the same

Frequency test and descriptive analysis were run for the quality of information of all the POMI sources. On the whole, with the exception of organizational sources: educational program by HMO/hospital and national/local medical information services, all the other sources were ranked lower for the quality of information obtained by the healthcare professionals in comparison to the patients (**Table 11**).

To further test whether there are significant differences between health care professionals independent sample t-test and z-test were run to compare the population mean of the quality of information obtained from sources of POMI between two groups (Table 13).

Results indicated that there were 1) high significant differences in the views of two groups about the quality of information obtained from talking with a support group, talking with other patients, email/chat room with other patients, email from relatives/friends/acquaintances, narratives (written stories by other patients), books, Internet/medical websites, TV/radio, News paper magazines and films/movies, 2) low significant differences in differences in the views or two groups about the quality of information obtained from talking with nurse/other health professionals, email/chat room with a support group, telephone/helpline and audio/video tapes and 3) no significant differences for the other sources (**Table 12**). **Table 13** lists in detail the views about the quality of information from sources of POMI for both the groups. Comparison of the analysis for both the groups support hypothesis 3 for a majority of sources.

**Hypothesis 4**

The fourth hypothesis proposed that health care professional's perception of the expected quality of information from future sources of POMI will be different from cancer patients' perception of the same.

Frequency test and descriptive analysis were run for the quality of information of all the POMI sources. All the sources were ranked lower for the quality of information obtained by the healthcare professionals in comparison to the patients (**Table 14**).

To further test whether there are significant differences between health care professionals independent sample t-test or z-test were run to compare the population mean of the quality of information obtained from sources of POMI between two groups (Table 13). Results indicated that there were 1) significant differences in the views of two groups about the quality of information obtained from talking with other patients, talking with

relatives/friends/acquaintances, email/chat room with other patients, email from relatives/friends/acquaintances, narratives (written stories by other patients), Internet/medical websites, Newspaper/magazines, films/movies, talking with nurse/other health professionals, email/chat room with a support group, telephone/helpline and TV/radio (**Table 15**). **Table 16** lists in detail the views about the quality of information from sources of POMI for both the groups. Comparison of the analysis for both the groups support hypothesis 4 for a majority of sources.

## Hypothesis 5

The fifth hypothesis proposed that health care professional's perception about the predictors of information seeking behavior of cancer patients will be different from patients' perception of the same.

Analysis form Chen Wang's study indicates that 1) age, race, education and computer ownership have some predicting power for the use of sources and 2) other demographic factors do not influence the information seeking behavior of the patient (**Table 17**).

There is a significant difference in the health care professionals' views of the predictors of the information seeking behavior of the patients. Analysis from this study indicates that 1) majority of healthcare professionals feel that age, race, education, working status, household income and computer access impact the information seeking behavior of the patients, 2) slightly more than half of healthcare professionals feel that general health condition and gender impact the information seeking behavior of the patients and 3) less that half of the healthcare professional feel that insurance coverage impact the information seeking behavior of the patients (**Table 18**).

**Table 4**: Demographics of Medical Information Sources Survey Responders

| Characteristics | Demographics Questions | N | Analysis (%) |
|---|---|---|---|
| **Position** | Oncologists | 42 | 63.6% |
| | Oncology Nurse | 17 | 25.7% |
| | Research Nurse | 2 | 3.0% |
| | Research Administrator | 2 | 3.0% |
| | Others | 3 | 4.5% |
| **Gender** | Male | 34 | 51.5% |
| | Female | 32 | 48.4% |
| **Age** | 21-30 | 2 | 3.1% |
| | 31-40 | 21 | 33.3% |
| | 41-50 | 26 | 41.2% |
| | 51-60 | 12 | 19.0% |
| | 61-70 | 1 | 1.5% |
| | 71-80 | 1 | 1.5% |
| **Years of Practice** | 1-5 | 7 | 11.8% |
| | 6-10 | 12 | 20.3% |
| | 11-15 | 14 | 23.7% |
| | 16-20 | 12 | 20.3% |
| | 21-25 | 8 | 13.5% |
| | 26-30 | 3 | 5.0% |
| | >30 | 3 | 5.0% |
| **Use of Internet** | No | 2 | 3.0% |
| | Yes | 61 | 92.4% |
| **Type of Cancer** | Breast | 10 | 15.1% |
| | Gastro Intestinal | 11 | 16.6% |
| | Head & Neck | 3 | 4.5% |
| | Haematological Malignancies | 5 | 7.5% |
| | Lung | 19 | 28.7% |
| | Urinary/Genitourinary | 4 | 6.0% |
| | Others | 14 | 21.2% |
| **Geographic Location** | Urban | 20 | 30.3% |
| | Counties outside metro statistical area | 6 | 9.0% |
| | Metropolitan area | 37 | 56.0% |
| | Rural health professional shortage area | 3 | 4.5% |
| **Practice Setting** | Solo | 6 | 9.0% |
| | Free-standing clinic | 3 | 4.5% |
| | Hospital | 14 | 21.2% |
| | Group office | 8 | 12.1% |
| | Medical School | 33 | 50.0% |
| | Other | 2 | 3.0% |

**Table 5: Demographic Differences between Health Care Professionals**

| **Demographics** | **Differences among health care professionals** |
|---|---|
| | P value (N=66) |
| Years of Practice | 0.089 |
| Geographic location of practice | 0.810 |
| Type of practice setting | **0.000** |
| Use of Internet | 0.148 |
| Age | 0.014 |
| Type of Cancer treated frequently | 0.235 |
| Gender | **0.000** |

**Table 6: Demographic Differences between types of Cancer Treated**

| **Demographics** | **Differences among type of cancer treated** |
|---|---|
| | P value (N=66) |
| Years of Practice | 0.929 |
| Geographic location of practice | 0.858 |
| Type of practice setting | 0.670 |
| Use of Internet | 0.547 |
| Age | 0.879 |
| Position | 0.235 |
| Gender | 0.047 |

**Table 7: Ranking Comparison for Past POMI Sources (Physician vs. Patient)**

| | | Physician | | | Patient | |
|---|---|---|---|---|---|---|
| **Source-Past** | **Ranking** | **N** | **Yes %** | **Ranking** | **N** | **Yes %** |
| | | | **(N=66)** | | | **(N=257)** |
| Talking with physician or physicians assistant | 1 | 65 | 98.5% | 1 | 252 | 98.1% |
| Talking with nurse/other health professionals | 2 | 64 | 97.0% | 2 | 215 | 83.7% |
| Talking with other patients | 3 | 63 | 95.5% | 4 | 133 | 51.8% |
| Talking with relatives/friends/acquaintances | 4 | 62 | 93.9% | 3 | 169 | 65.8% |
| Internet/medical websites | 5 | 62 | 93.9% | 7 | 101 | 39.3% |
| Medical leaflets/pamphlets | 6 | 61 | 92.4% | 5 | 129 | 50.2% |
| Talking with a support group | 7 | 59 | 89.4% | 12 | 42 | 16.3% |
| Newspaper/magazines | 8 | 58 | 89.2% | 8 | 97 | 37.7% |
| TV/radio | 9 | 56 | 84.8% | 9 | 69 | 26.8% |
| National/local medical information services | 10 | 54 | 83.1% | 14 | 38 | 14.8% |
| Books | 11 | 53 | 80.3% | 6 | 128 | 49.8% |
| Email from relatives/friends/acquaintances | 12 | 45 | 69.2% | 13 | 39 | 15.2% |
| Email/chat room with a support group | 13 | 45 | 68.2% | 21 | 13 | 5.1% |
| Narratives(written stories by other patients) | 14 | 42 | 63.6% | 11 | 49 | 19.1% |
| Educational program by HMO/hospital | 15 | 39 | 60.0% | 16 | 24 | 9.3% |
| Telephone/helpline | 16 | 38 | 58.5% | 19 | 18 | 7.0% |
| Email/chat room with other patients | 17 | 38 | 57.6% | 22 | 9 | 3.5% |
| Audio/video tapes | 18 | 34 | 51.5% | 17 | 24 | 9.3% |
| Medical Journals | 19 | 33 | 50.0% | 10 | 54 | 21.0% |
| Films/movies | 20 | 32 | 49.2% | 15 | 25 | 9.7% |
| Email from physician or physician's assistant | 21 | 24 | 36.4% | 18 | 20 | 7.8% |
| Email from nurse/other health professionals | 22 | 24 | 36.4% | 20 | 16 | 6.2% |

**Table 8: Ranking comparison by Different Source Type (Physician vs. Patient)**

| **Source-Past** | | **Physician** | **Patient** | **Proportion significance (P Value)** |
|---|---|---|---|---|
| **Human Sources** | **Frequency Utilization** | 89.7% | 55.8% | |
| Talking with physician or physicians assistant | | 1 | 1 | .4090 |
| Talking with nurse/other health professionals | | 2 | 2 | .0025 |
| Talking with a support group | | 7 | 12 | .0000 |
| Talking with other patients | | 3 | 4 | .0000 |
| Talking with relatives/friends/acquaintances | | 4 | 3 | .0000 |
| Narratives(written stories by other patients) | | 14 | 11 | .0000 |
| **Printed Media** | **Frequency Utilization** | 78.0% | 39.7% | |
| Medical leaflets/pamphlets | | 6 | 5 | .0000 |
| Books | | 11 | 6 | .0000 |
| Medical Journals | | 19 | 10 | .0000 |
| Newspaper/magazines | | 8 | 8 | .0000 |
| **Networked Sources** | **Frequency Utilization** | 60.0% | 12.0% | |
| Email from physician or physician's assistant | | 21 | 18 | .0000 |
| Email from nurse/other health professionals | | 22 | 20 | .0000 |
| Email/chat room with a support group | | 13 | 21 | .0000 |
| Email/chat room with other patients | | 17 | 22 | .0000 |
| Email from relatives/friends/acquaintances | | 12 | 13 | .0000 |
| Internet/medical websites | | 6 | 7 | .0000 |
| Telephone/helpline | | 13 | 20 | .0000 |
| **Broadcast Media** | **Frequency Utilization** | 67.0% | 18.25 | |
| TV/radio | | 9 | 9 | .0000 |
| Films/movies | | 20 | 15 | .0000 |
| **Organizational Sources** | **Frequency Utilization** | 71.6% | 12.1% | |
| Educational program by HMO/hospital | | 15 | 16 | .0000 |
| National/local medical information services | | 10 | 14 | .0000 |
| **Other Sources** | **Frequency Utilization** | 51.5% | 9.3% | |
| Audio/video tapes | | 18 | 17 | .0000 |

**Table 9: Ranking Comparison for Future POMI Sources (Physician vs. Patient)**

| | | Physician | | | Patient | |
|---|---|---|---|---|---|---|
| **Source-Future** | **Ranking** | **N** | **Yes %** | **Ranking** | **N** | **Yes %** |
| | | | **(N=66)** | | | **(N=257)** |
| Talking with physician or physicians assistant | 1 | 64 | 97.0% | 1 | 219 | 85.2% |
| Talking with nurse/other health professionals | 2 | 61 | 92.4% | 2 | 178 | 69.3% |
| National/local medical information services | 3 | 58 | 89.2% | 14 | 31 | 12.1% |
| Medical leaflets/pamphlets | 4 | 57 | 86.4% | 6 | 99 | 38.5% |
| Talking with a support group | 5 | 52 | 78.8% | 12 | 38 | 14.8% |
| Internet/medical websites | 6 | 51 | 78.5% | 7 | 87 | 33.9% |
| Educational program by HMO/hospital | 7 | 43 | 66.2% | 15 | 28 | 10.9% |
| Books | 8 | 43 | 66.2% | 5 | 105 | 40.9% |
| Talking with other patients | 9 | 41 | 62.1% | 4 | 111 | 43.2% |
| Medical Journals | 10 | 39 | 59.1% | 10 | 51 | 19.8% |
| Audio/video tapes | 11 | 33 | 50.0% | 17 | 16 | 6.2% |
| Email from physician or physician's assistant | 12 | 31 | 47.0% | 16 | 18 | 7.0% |
| Telephone/helpline | 13 | 28 | 43.1% | 20 | 12 | 4.7% |
| Talking with relatives/friends/acquaintances | 14 | 28 | 42.4% | 3 | 122 | 47.5% |
| Newspaper/magazines | 15 | 27 | 41.5% | 8 | 75 | 29.2% |
| Narratives(written stories by other patients) | 16 | 27 | 40.9% | 11 | 41 | 16.0% |
| Email from nurse/other health professionals | 17 | 26 | 39.4% | 19 | 14 | 5.4% |
| Email/chat room with a support group | 18 | 24 | 36.4% | 21 | 11 | 4.3% |
| TV/radio | 19 | 21 | 31.8% | 9 | 56 | 21.8% |
| Email from relatives/friends/acquaintances | 20 | 17 | 26.2% | 13 | 122 | 12.1% |
| Email/chat room with other patients | 21 | 16 | 24.2% | 22 | 6 | 2.3% |
| Films/movies | 22 | 13 | 20.0% | 18 | 15 | 5.8% |

**Table 10: Ranking Comparison for Future POMI Sources by Different Source Type (Physician vs. Patient)**

| Sources | | Physician | Patient | Proportion Significance (P-value) |
|---|---|---|---|---|
| **Human Sources** | **Frequency Utilization** | 69.0% | 46.0% | |
| Talking with physician or physicians assistant | | 1 | 1 | .0048 |
| Talking with nurse/other health professionals | | 2 | 2 | .0025 |
| Talking with a support group | | 5 | 12 | .0000 |
| Talking with other patients | | 9 | 4 | .0030 |
| Talking with relatives/friends/acquaintances | | 14 | 3 | .2327 |
| Narratives(written stories by other patients) | | 16 | 11 | .0000 |
| **Printed Media** | **Frequency Utilization** | 63.3% | 32.1% | |
| Medical leaflets/pamphlets | | 4 | 6 | .0000 |
| Books | | 8 | 5 | .0039 |
| Medical Journals | | 10 | 10 | .0000 |
| Newspaper/magazines | | 15 | 8 | .3360 |
| **Networked Sources** | **Frequency Utilization** | 42.1% | 9.95% | |
| Email from physician or physician's assistant | | 12 | 16 | .0000 |
| Email from nurse/other health professionals | | 17 | 19 | .0000 |
| Email/chat room with a support group | | 18 | 21 | .0000 |
| Email/chat room with other patients | | 21 | 22 | .0000 |
| Email from relatives/friends/acquaintances | | 20 | 13 | .0026 |
| Internet/medical websites | | 6 | 7 | .0000 |
| Telephone/helpline | | 13 | 20 | .0000 |
| **Broadcast Media** | **Frequency Utilization** | 25.9% | 13.8% | |
| TV/radio | | 19 | 9 | .0436 |
| Films/movies | | 22 | 18 | .0002 |
| **Organizational Sources** | **Frequency Utilization** | 77.7% | 11.5% | |
| Educational program by HMO/hospital | | 7 | 15 | .0000 |
| National/local medical information services | | 3 | 14 | .0000 |
| **Other Sources** | **Frequency Utilization** | 50.0% | 6.2% | |
| Audio/video tapes | | 11 | 17 | .0000 |

**Table 11: Comparison of Quality of Information from POMI Sources (PAST)**

| Source | Physician | N=66 | Patient | N=257 |
|---|---|---|---|---|
| **Human Sources** | Quality Mean | **N** | Quality Mean | **N** |
| Talking with physician or physicians assistant | 6.2 | 65 | 6.29 | 250 |
| Talking with nurse/other health professionals | 5.62 | 64 | 6.06 | 215 |
| Talking with a support group | 4.35 | 60 | 4.64 | 44 |
| Talking with other patients | 3.75 | 63 | 5.12 | 130 |
| Talking with relatives/friends/acquaintances | 2.68 | 63 | 4.87 | 166 |
| Narratives(written stories by other patients) | 3.8 | 44 | 5.1 | 48 |
| **Printed Media** | | | | |
| Medical leaflets/pamphlets | 5.31 | 61 | 5.59 | 126 |
| Books | 4.79 | 53 | 5.56 | 126 |
| Medical Journals | 5.64 | 36 | 5.83 | 99 |
| Newspaper/magazines | 3.11 | 56 | 4.72 | 97 |
| **Networked Sources** | | | | |
| Email from physician or physician's assistant | 5.24 | 25 | 5.68 | 19 |
| Email from nurse/other health professionals | 4.96 | 25 | 5.21 | 14 |
| Email/chat room with a support group | 3.42 | 45 | 4.85 | 13 |
| Email/chat room with other patients | 3.31 | 39 | 5.11 | 9 |
| Email from relatives/friends/acquaintances | 2.58 | 45 | 4.61 | 38 |
| Internet/medical websites | 4.2 | 60 | 5.68 | 99 |
| Telephone/helpline | 4 | 39 | 5.11 | 19 |
| **Broadcast Media** | | | | |
| TV/radio | 2.93 | 54 | 4.44 | 68 |
| Films/movies | 2.51 | 35 | 5.08 | 26 |
| **Organizational Sources** | | | | |
| Educational program by HMO/hospital | 5.35 | 40 | 5.23 | 26 |
| National/local medical information services | 5.45 | 53 | 5.39 | 36 |
| **Other Sources** | | | | |
| Audio/video tapes | 4.36 | 36 | 5.31 | 26 |

**Table 12: Quality Significance Test for Information from POMI Sources (PAST)**

| Source | P value |
|---|---|
| Talking with physician or physicians assistant | 0.2709 |
| Talking with nurse/other health professionals | 0.0013 |
| Talking with a support group | 0.1685 |
| Talking with other patients | 0.0000 |
| Talking with relatives/friends/acquaintances | 0.0000 |
| Email from physician or physician's assistant | 0.3460 |
| Email from nurse/other health professionals | 0.6310 |
| Email/chat room with a support group | 0.0075 |
| Email/chat room with other patients | 0.0000 |
| Email from relatives/friends/acquaintances | 0.0000 |
| Educational program by HMO/hospital | 0.3707 |
| National/local medical information services | 0.4207 |
| Medical leaflets/pamphlets | 0.0571 |
| Narratives(written stories by other patients) | 0.0000 |
| Books | 0.0002 |
| Medical Journals | 0.2358 |
| Internet/medical websites | 0.0000 |
| Telephone/helpline | 0.0071 |
| TV/radio | 0.0000 |
| Newspaper/magazines | 0.0000 |
| Audio/video tapes | 0.0096 |
| Films/movies | 0.0000 |

**Table 13: Detailed Description of Quality of Information from POMI Sources (PAST)**

| Sources | N | Physician | | N | Patient | |
|---|---|---|---|---|---|---|
| **Talking with Physician or Physician's Assistant** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 1.5% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 1.5% | | Below Average = 3 | 1.2% |
| | **65** | Average = 4 | 3.1% | 250 | Average = 4 | 4.8% |
| | | Good = 5 | 15.4% | | Good = 5 | 12.4% |
| | | Very Good = 6 | 26.2% | | Very Good = 6 | 26.8% |
| | | Excellent = 7 | 52.3% | | Excellent = 7 | 54.8% |
| | | **Mean** | **6.2** | | **Mean** | **6.29** |
| **Talking with Nurse or Other Health Professionals** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 0.0% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 3.1% | | Below Average = 3 | 0.5% |
| | **64** | Average = 4 | 12.5% | 215 | Average = 4 | 6.5% |
| | | Good = 5 | 20.3% | | Good = 5 | 20.0% |
| | | Very Good = 6 | 46.9% | | Very Good = 6 | 33.0% |
| | | Excellent = 7 | 17.2% | | Excellent = 7 | 40.0% |
| | | **Mean** | **5.62** | | **Mean** | **6.06** |
| **Talking with a Support Group** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 6.8% |
| | | Poor = 2 | 6.7% | | Poor = 2 | 4.5% |
| | | Below Average = 3 | 11.7% | | Below Average = 3 | 9.1% |
| | **60** | Average = 4 | 38.3% | 44 | Average = 4 | 29.5% |
| | | Good = 5 | 30.0% | | Good = 5 | 20.5% |
| | | Very Good = 6 | 10.0% | | Very Good = 6 | 6.8% |
| | | Excellent = 7 | 3.3% | | Excellent = 7 | 22.7% |
| | | **Mean** | **4.35** | | **Mean** | **4.64** |

**Table 13 Continued**

| Sources | N | Physician | | N | Patient | |
|---|---|---|---|---|---|---|
| **Talking with Other Patients** | | Very Poor = 1 | 4.8% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 7.9% | | Poor = 2 | 3.8% |
| | | Below Average = 3 | 27.0% | | Below Average = 3 | 5.4% |
| | **63** | Average = 4 | 38.1% | 130 | Average = 4 | 25.4% |
| | | Good = 5 | 14.3% | | Good = 5 | 25.4% |
| | | Very Good = 6 | 6.3% | | Very Good = 6 | 20.0% |
| | | Excellent = 7 | 1.6% | | Excellent = 7 | 20.0% |
| | | **Mean** | **3.75** | | **Mean** | **5.12** |
| **Talking with Relatives, Friends, and Acquaintances** | | Very Poor = 1 | 19.0% | | Very Poor = 1 | 3.0% |
| | | Poor = 2 | 23.8% | | Poor = 2 | 7.2% |
| | | Below Average = 3 | 34.9% | | Below Average = 3 | 9.0% |
| | **63** | Average = 4 | 17.5% | 166 | Average = 4 | 19.3% |
| | | Good = 5 | 1.6% | | Good = 5 | 25.3% |
| | | Very Good = 6 | 3.2% | | Very Good = 6 | 14.5% |
| | | Excellent = 7 | 0.0% | | Excellent = 7 | 21.7% |
| | | **Mean** | **2.68** | | **Mean** | **4.87** |
| **Email from Physician or Physician's Assistant** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 5.3% |
| | | Poor = 2 | 8.0% | | Poor = 2 | 2.8% |
| | | Below Average = 3 | 4.0% | | Below Average = 3 | 5.3% |
| | **25** | Average = 4 | 16.0% | 19 | Average = 4 | 5.3% |
| | | Good = 5 | 20.0% | | Good = 5 | 15.8% |
| | | Very Good = 6 | 32.0% | | Very Good = 6 | 31.6% |
| | | Excellent = 7 | 20.0% | | Excellent = 7 | 36.8% |
| | | **Mean** | **5.24** | | **Mean** | **5.68** |

**Table 13 Continued**

| Sources | N | Physician | | N | Patient | |
|---|---|---|---|---|---|---|
| **Email from Nurse or Other Health Professionals** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 7.1% |
| | | Poor = 2 | 8.0% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 8.0% | | Below Average = 3 | 7.1% |
| | **25** | Average = 4 | 24.0% | 14 | Average = 4 | 14.3% |
| | | Good = 5 | 8.0% | | Good = 5 | 21.4% |
| | | Very Good = 6 | 44.0% | | Very Good = 6 | 21.4% |
| | | Excellent = 7 | 8.0% | | Excellent = 7 | 28.6% |
| | | **Mean** | **4.96** | | **Mean** | **5.21** |
| **Email or Chat-room with a Support Group** | | Very Poor = 1 | 6.7% | | Very Poor = 1 | 7.7% |
| | | Poor = 2 | 13.3% | | Poor = 2 | 7.7% |
| | | Below Average = 3 | 24.4% | | Below Average = 3 | 7.7% |
| | **45** | Average = 4 | 42.2% | 13 | Average = 4 | 23.1% |
| | | Good = 5 | 13.3% | | Good = 5 | 7.7% |
| | | Very Good = 6 | 0.0% | | Very Good = 6 | 15.4% |
| | | Excellent = 7 | 0.0% | | Excellent = 7 | 30.8% |
| | | **Mean** | **3.42** | | **Mean** | **4.85** |
| **Email or Chat-room with Other Patients** | | Very Poor = 1 | 2.6% | | Very Poor = 1 | 11.1% |
| | | Poor = 2 | 15.4% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 41.0% | | Below Average = 3 | 11.1% |
| | | Average = 4 | 33.3% | 9 | Average = 4 | 11.1% |
| | 39 | Good = 5 | 5.1% | | Good = 5 | 11.1% |
| | | Very Good = 6 | 2.6% | | Very Good = 6 | 22.2% |
| | | Excellent = 7 | 0.0% | | Excellent = 7 | 33.3% |
| | | **Mean** | **3.31** | | **Mean** | **5.11** |

**Table 13 Continued**

| Sources | N | Physician | | N | Patient | |
|---|---|---|---|---|---|---|
| **Email from Relatives, Friends, and Acquaintances** | | Very Poor = 1 | 22.2% | | Very Poor = 1 | 5.3% |
| | | Poor = 2 | 20.0% | | Poor = 2 | 13.2% |
| | | Below Average = 3 | 40.0% | | Below Average = 3 | 7.9% |
| | **45** | Average = 4 | 15.6% | 38 | Average = 4 | 15.8% |
| | | Good = 5 | 0.0% | | Good = 5 | 23.7% |
| | | Very Good = 6 | 2.2% | | Very Good = 6 | 15.8% |
| | | Excellent = 7 | 0.0% | | Excellent = 7 | 18.4% |
| | | **Mean** | **2.58** | | **Mean** | **4.61** |
| **Educational Programs by HMO or Hospital** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 3.8% |
| | | Poor = 2 | 0.0% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 7.5% | | Below Average = 3 | 15.4% |
| | **40** | Average = 4 | 10.0% | 26 | Average = 4 | 7.7% |
| | | Good = 5 | 35.0% | | Good = 5 | 23.1% |
| | | Very Good = 6 | 35.0% | | Very Good = 6 | 23.1% |
| | | Excellent = 7 | 12.5% | | Excellent = 7 | 26.9% |
| | | **Mean** | **5.35** | | **Mean** | **5.23** |
| **National/Local Medical Information Services** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 2.8% |
| | | Poor = 2 | 1.9% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 5.7% | | Below Average = 3 | 8.3% |
| | **53** | Average = 4 | 11.3% | 36 | Average = 4 | 13.9% |
| | | Good = 5 | 24.5% | | Good = 5 | 22.2% |
| | | Very Good = 6 | 39.6% | | Very Good = 6 | 25.0% |
| | | Excellent = 7 | 17.0% | | Excellent = 7 | 27.8% |
| | | **Mean** | **5.45** | | **Mean** | **5.39** |

**Table 13 Continued**

| Sources | N | Physician | | N | Patient | |
|---|---|---|---|---|---|---|
| **Medical Leaflets or Pamphlets** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 1.6% |
| | | Poor = 2 | 0.0% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 3.3% | | Below Average = 3 | 3.2% |
| | **61** | Average = 4 | 21.3% | 126 | Average = 4 | 11.9% |
| | | Good = 5 | 32.8% | | Good = 5 | 25.4% |
| | | Very Good = 6 | 26.2% | | Very Good = 6 | 32.5% |
| | | Excellent = 7 | 16.4% | | Excellent = 7 | 25.4% |
| | | **Mean** | **5.31** | | **Mean** | **5.59** |
| **Narratives** | | Very Poor = 1 | 2.3% | | Very Poor = 1 | 4.2% |
| | | Poor = 2 | 6.8% | | Poor = 2 | 2.1% |
| | | Below Average = 3 | 40.9% | | Below Average = 3 | 8.3% |
| | **44** | Average = 4 | 22.7% | 48 | Average = 4 | 18.8% |
| | | Good = 5 | 18.2% | | Good = 5 | 14.6% |
| | | Very Good = 6 | 4.5% | | Very Good = 6 | 35.4% |
| | | Excellent = 7 | 4.5% | | Excellent = 7 | 16.7% |
| | | **Mean** | **3.8** | | **Mean** | **5.1** |
| **Books** | | Very Poor = 1 | 1.9% | | Very Poor = 1 | 1.6% |
| | | Poor = 2 | 0.0% | | Poor = 2 | 3.2% |
| | | Below Average = 3 | 7.5% | | Below Average = 3 | 2.4% |
| | **53** | Average = 4 | 35.8% | 126 | Average = 4 | 11.1% |
| | | Good = 5 | 26.4% | | Good = 5 | 21.4% |
| | | Very Good = 6 | 18.9% | | Very Good = 6 | 33.3% |
| | | Excellent = 7 | 9.4% | | Excellent = 7 | 27.0% |
| | | **Mean** | **4.79** | | **Mean** | **5.56** |

**Table 13 Continued**

| Sources | N | Physician | | N | Patient | |
|---|---|---|---|---|---|---|
| **Medical Journals** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 2.8% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 2.8% | | Below Average = 3 | 1.9% |
| | **36** | Average = 4 | 13.9% | 99 | Average = 4 | 13.0% |
| | | Good = 5 | 19.4% | | Good = 5 | 20.4% |
| | | Very Good = 6 | 30.6% | | Very Good = 6 | 29.6% |
| | | Excellent = 7 | 30.6% | | Excellent = 7 | 35.2% |
| | | **Mean** | **5.64** | | **Mean** | **5.83** |
| **Internet or Medical Websites** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 1.0% |
| | | Poor = 2 | 11.7% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 18.3% | | Below Average = 3 | 1.0% |
| | **60** | Average = 4 | 21.7% | 99 | Average = 4 | 13.1% |
| | | Good = 5 | 36.7% | | Good = 5 | 31.3% |
| | | Very Good = 6 | 10.0% | | Very Good = 6 | 20.2% |
| | | Excellent = 7 | 1.7% | | Excellent = 7 | 33.3% |
| | | **Mean** | **4.2** | | **Mean** | **5.68** |
| **Telephone or Helpline** | | Very Poor = 1 | 2.6% | | Very Poor = 1 | 5.3% |
| | | Poor = 2 | 10.3% | | Poor = 2 | 5.3% |
| | | Below Average = 3 | 23.1% | | Below Average = 3 | 5.3% |
| | **39** | Average = 4 | 30.8% | 19 | Average = 4 | 10.5% |
| | | Good = 5 | 17.9% | | Good = 5 | 31.6% |
| | | Very Good = 6 | 12.8% | | Very Good = 6 | 15.8% |
| | | Excellent = 7 | 2.6% | | Excellent = 7 | 26.3% |
| | | **Mean** | **4** | | **Mean** | **5.11** |

**Table 13 Continued**

| Sources | N | Physician | | N | Patient | |
|---|---|---|---|---|---|---|
| | | Very Poor = 1 | 14.8% | | Very Poor = 1 | 4.4% |
| | | Poor = 2 | 27.8% | | Poor = 2 | 5.9% |
| | | Below Average = 3 | 16.7% | | Below Average = 3 | 14.7% |
| **TV/Radio** | **54** | Average = 4 | 31.5% | 68 | Average = 4 | 30.9% |
| | | Good = 5 | 9.3% | | Good = 5 | 19.1% |
| | | Very Good = 6 | 0.0% | | Very Good = 6 | 10.3% |
| | | Excellent = 7 | 0.0% | | Excellent = 7 | 14.7% |
| | | **Mean** | **2.93** | | **Mean** | **4.44** |
| | | Very Poor = 1 | 7.1% | | Very Poor = 1 | 4.1% |
| | | Poor = 2 | 32.1% | | Poor = 2 | 2.1% |
| | | Below Average = 3 | 25.0% | | Below Average = 3 | 10.3% |
| **Newspapers/Magazines** | **56** | Average = 4 | 23.2% | 97 | Average = 4 | 25.8% |
| | | Good = 5 | 5.4% | | Good = 5 | 27.8% |
| | | Very Good = 6 | 5.4% | | Very Good = 6 | 18.6% |
| | | Excellent = 7 | 1.8% | | Excellent = 7 | 11.3% |
| | | **Mean** | **3.11** | | **Mean** | **4.72** |
| | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 3.8% |
| | | Poor = 2 | 8.3% | | Poor = 2 | 3.8% |
| | | Below Average = 3 | 16.7% | | Below Average = 3 | 3.8% |
| **Audio/Video Tapes** | **36** | Average = 4 | 30.6% | 26 | Average = 4 | 23.1% |
| | | Good = 5 | 30.6% | | Good = 5 | 11.5% |
| | | Very Good = 6 | 2.8% | | Very Good = 6 | 19.2% |
| | | Excellent = 7 | 11.1% | | Excellent = 7 | 34.6% |
| | | **Mean** | **4.36** | | **Mean** | **5.31** |

**Table 13 Continued**

| Sources | N | Physician | | N | Patient | |
|---|---|---|---|---|---|---|
| | | Very Poor = 1 | 25.7% | | Very Poor = 1 | 3.8% |
| | | Poor = 2 | 34.3% | | Poor = 2 | 3.8% |
| | | Below Average = 3 | 17.1% | | Below Average = 3 | 11.5% |
| **Films/Movies** | **35** | Average = 4 | 14.3% | 26 | Average = 4 | 11.5% |
| | | Good = 5 | 5.7% | | Good = 5 | 23.1% |
| | | Very Good = 6 | 2.9% | | Very Good = 6 | 23.1% |
| | | Excellent = 7 | 0.0% | | Excellent = 7 | 23.1% |
| | | **Mean** | **2.51** | | **Mean** | **5.08** |

**Table 14: Comparison of Quality of Information from POMI Sources (FUTURE)**

| Future | Physician | N=66 | Patient | N=257 |
|---|---|---|---|---|
| **Human Sources** | Quality Mean | **N** | Quality Mean | **N** |
| Talking with physician or physicians assistant | 6.42 | 64 | 6.45 | 220 |
| Talking with nurse/other health professionals | 5.85 | 61 | 6.21 | 182 |
| Talking with a support group | 4.89 | 54 | 5.05 | 38 |
| Talking with other patients | 4.36 | 42 | 5.23 | 111 |
| Talking with relatives/friends/acquaintances | 3.21 | 34 | 5.01 | 124 |
| Narratives(written stories by other patients) | 4.4 | 30 | 5.43 | 42 |
| **Printed Media** | | | | |
| Medical leaflets/pamphlets | 5.67 | 58 | 5.98 | 101 |
| Books | 4.91 | 47 | 5.81 | 106 |
| Medical Journals | 5.9 | 40 | 5.92 | 53 |
| Newspaper/magazines | 3.62 | 29 | 4.85 | 79 |
| **Networked Sources** | | | | |
| Email from physician or physician's assistant | 5.68 | 34 | 6.21 | 19 |
| Email from nurse/other health professionals | 5.52 | 29 | 6.17 | 12 |
| Email/chat room with a support group | 4.28 | 32 | 5.58 | 12 |
| Email/chat room with other patients | 3.9 | 20 | 6.67 | 6 |
| Email from relatives/friends/acquaintances | 3.52 | 21 | 4.81 | 32 |
| Internet/medical websites | 4.94 | 51 | 5.78 | 90 |
| Telephone/helpline | 4.29 | 31 | 5.64 | 11 |
| **Broadcast Media** | | | | |
| TV/radio | 3.69 | 26 | 4.6 | 58 |
| Films/movies | 3.33 | 18 | 5.38 | 16 |
| **Organizational Sources** | | | | |
| Educational program by HMO/hospital | 5.65 | 43 | 5.96 | 28 |
| National/local medical information services | 5.9 | 58 | 5.94 | 32 |
| **Other Sources** | | | | |
| Audio/video tapes | 4.63 | 35 | 5.33 | 15 |

**Table 15: Quality Significance Test for Information from POMI Sources (FUTURE)**

| Future-Quality | P value |
|---|---|
| Talking with physician or physicians assistant | .3974 |
| Talking with nurse/other health professionals | .0049 |
| Talking with a support group | .2946 |
| Talking with other patients | .0000 |
| Talking with relatives/friends/acquaintances | .0000 |
| Email from physician or physician's assistant | .0352 |
| Email from nurse/other health professionals | .1980 |
| Email/chat room with a support group | .0062 |
| Email/chat room with other patients | .0100 |
| Email from relatives/friends/acquaintances | .0050 |
| Educational program by HMO/hospital | .1401 |
| National/local medical information services | .4286 |
| Medical leaflets/pamphlets | .0268 |
| Narratives(written stories by other patients) | .0002 |
| Books | .0000 |
| Medical Journals | .4681 |
| Internet/medical websites | .0000 |
| Telephone/helpline | .0064 |
| TV/radio | .0180 |
| Newspaper/magazines | .0001 |
| Audio/video tapes | .0375 |
| Films/movies | .0050 |

**Table 16: Detailed Description of Quality of Information from POMI Sources (FUTURE)**

| Sources | N | Physician | | N | Patient | |
|---|---|---|---|---|---|---|
| **Talking with Physician or Physician's Assistant** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 0.0% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 0.0% | | Below Average = 3 | 0.0% |
| | 64 | Average = 4 | 4.7% | 220 | Average = 4 | 3.2% |
| | | Good = 5 | 7.8% | | Good = 5 | 10.0% |
| | | Very Good = 6 | 28.1% | | Very Good = 6 | 25.0% |
| | | Excellent = 7 | 59.4% | | Excellent = 7 | 61.8% |
| | | **Mean** | **6.42** | | **Mean** | **6.45** |
| **Talking with Nurse or Other Health Professionals** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 0.0% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 1.6% | | Below Average = 3 | 0.5% |
| | 61 | Average = 4 | 6.6% | 182 | Average = 4 | 6.6% |
| | | Good = 5 | 23.0% | | Good = 5 | 12.1% |
| | | Very Good = 6 | 42.6% | | Very Good = 6 | 33.0% |
| | | Excellent = 7 | 26.2% | | Excellent = 7 | 47.8% |
| | | **Mean** | **5.85** | | **Mean** | **6.21** |
| **Talking with a Support Group** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 2.6% |
| | | Poor = 2 | 0.0% | | Poor = 2 | 2.6% |
| | | Below Average = 3 | 9.3% | | Below Average = 3 | 7.9% |
| | 54 | Average = 4 | 27.8% | 38 | Average = 4 | 26.3% |
| | | Good = 5 | 35.2% | | Good = 5 | 21.1% |
| | | Very Good = 6 | 20.4% | | Very Good = 6 | 13.2% |
| | | Excellent = 7 | 7.4% | | Excellent = 7 | 26.3% |
| | | **Mean** | **4.89** | | **Mean** | **5.05** |

**Table 16 Continued**

| Sources | N | Physician | | N | Patient | |
|---|---|---|---|---|---|---|
| **Talking with Other Patients** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 4.8% | | Poor = 2 | 1.8% |
| | | Below Average = 3 | 14.3% | | Below Average = 3 | 3.6% |
| | 42 | Average = 4 | 38.1% | 111 | Average = 4 | 28.8% |
| | | Good = 5 | 31.0% | | Good = 5 | 23.4% |
| | | Very Good = 6 | 7.1% | | Very Good = 6 | 19.8% |
| | | Excellent = 7 | 4.8% | | Excellent = 7 | 22.5% |
| | | **Mean** | **4.36** | | **Mean** | **5.23** |
| **Talking with Relatives, Friends, and Acquaintances** | | Very Poor = 1 | 8.8% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 14.7% | | Poor = 2 | 6.5% |
| | | Below Average = 3 | 38.2% | | Below Average = 3 | 9.7% |
| | 34 | Average = 4 | 26.5% | 124 | Average = 4 | 21.0% |
| | | Good = 5 | 8.8% | | Good = 5 | 27.4% |
| | | Very Good = 6 | 2.9% | | Very Good = 6 | 10.5% |
| | | Excellent = 7 | 0.0% | | Excellent = 7 | 25.0% |
| | | **Mean** | **3.21** | | **Mean** | **5.01** |
| **Email from Physician or Physician's Assistant** | | Very Poor = 1 | 2.9% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 2.9% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 0.0% | | Below Average = 3 | 0.0% |
| | 34 | Average = 4 | 5.9% | 19 | Average = 4 | 0.0% |
| | | Good = 5 | 17.6% | | Good = 5 | 21.1% |
| | | Very Good = 6 | 47.1% | | Very Good = 6 | 36.8% |
| | | Excellent = 7 | 23.5% | | Excellent = 7 | 42.1% |
| | | **Mean** | **5.68** | | **Mean** | **6.21** |

**Table 16 Continued**

| Sources | N | Physician | | N | Patient | |
|---|---|---|---|---|---|---|
| **Email from Nurse or Other Health Professionals** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 0.0% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 10.3% | | Below Average = 3 | 0.0% |
| | 29 | Average = 4 | 10.3% | 12 | Average = 4 | 8.3% |
| | | Good = 5 | 17.2% | | Good = 5 | 8.3% |
| | | Very Good = 6 | 41.4% | | Very Good = 6 | 41.7% |
| | | Excellent = 7 | 20.7% | | Excellent = 7 | 41.7% |
| | | **Mean** | **5.52** | | **Mean** | **6.17** |
| **Email or Chat-room with a Support Group** | | Very Poor = 1 | 3.1% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 3.1% | | Poor = 2 | 8.3% |
| | | Below Average = 3 | 18.8% | | Below Average = 3 | 0.0% |
| | 32 | Average = 4 | 31.3% | 12 | Average = 4 | 16.7% |
| | | Good = 5 | 28.1% | | Good = 5 | 16.7% |
| | | Very Good = 6 | 12.5% | | Very Good = 6 | 16.7% |
| | | Excellent = 7 | 3.1% | | Excellent = 7 | 41.7% |
| | | **Mean** | **4.28** | | **Mean** | **5.58** |
| **Email or Chat-room with Other Patients** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 5.0% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 25.0% | | Below Average = 3 | 0.0% |
| | | Average = 4 | 45.0% | | Average = 4 | 0.0% |
| | 20 | Good = 5 | 25.0% | 6 | Good = 5 | 0.0% |
| | | Very Good = 6 | 0.0% | | Very Good = 6 | 33.3% |
| | | Excellent = 7 | 0.0% | | Excellent = 7 | 66.7% |
| | | **Mean** | **3.9** | | **Mean** | **6.67** |

**Table 16 Continued**

| Sources | N | Physician | | N | Patient | |
|---|---|---|---|---|---|---|
| **Email from Relatives, Friends, and Acquaintances** | | Very Poor = 1 | 4.8% | | Very Poor = 1 | 3.1% |
| | | Poor = 2 | 4.8% | | Poor = 2 | 12.5% |
| | | Below Average = 3 | 52.4% | | Below Average = 3 | 3.1% |
| | 21 | Average = 4 | 23.8% | 32 | Average = 4 | 12.5% |
| | | Good = 5 | 0.0% | | Good = 5 | 34.4% |
| | | Very Good = 6 | 14.3% | | Very Good = 6 | 18.8% |
| | | Excellent = 7 | 0.0% | | Excellent = 7 | 15.6% |
| | | **Mean** | **3.52** | | **Mean** | **4.81** |
| **Educational Programs by HMO or Hospital** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 0.0% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 2.3% | | Below Average = 3 | 7.1% |
| | 43 | Average = 4 | 9.3% | 28 | Average = 4 | 7.1% |
| | | Good = 5 | 30.2% | | Good = 5 | 17.9% |
| | | Very Good = 6 | 37.2% | | Very Good = 6 | 17.9% |
| | | Excellent = 7 | 20.9% | | Excellent = 7 | 50.0% |
| | | **Mean** | **5.65** | | **Mean** | **5.96** |
| **National/Local Medical Information Services** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 0.0% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 1.7% | | Below Average = 3 | 0.0% |
| | 58 | Average = 4 | 5.2% | 32 | Average = 4 | 12.5% |
| | | Good = 5 | 19.0% | | Good = 5 | 21.9% |
| | | Very Good = 6 | 50.0% | | Very Good = 6 | 25.0% |
| | | Excellent = 7 | 24.1% | | Excellent = 7 | 40.6% |
| | | **Mean** | **5.9** | | **Mean** | **5.94** |

**Table 16 Continued**

| Sources | N | Physician | | N | Patient | |
|---|---|---|---|---|---|---|
| **Medical Leaflets or Pamphlets** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 0.0% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 1.7% | | Below Average = 3 | 1.0% |
| | 58 | Average = 4 | 5.2% | 101 | Average = 4 | 9.9% |
| | | Good = 5 | 39.7% | | Good = 5 | 17.8% |
| | | Very Good = 6 | 31.0% | | Very Good = 6 | 32.7% |
| | | Excellent = 7 | 22.4% | | Excellent = 7 | 38.6% |
| | | **Mean** | **5.67** | | **Mean** | **5.98** |
| **Narratives** | | Very Poor = 1 | 0.0% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 3.3% | | Poor = 2 | 2.4% |
| | | Below Average = 3 | 20.0% | | Below Average = 3 | 4.8% |
| | 30 | Average = 4 | 26.7% | 42 | Average = 4 | 14.3% |
| | | Good = 5 | 40.0% | | Good = 5 | 28.6% |
| | | Very Good = 6 | 3.3% | | Very Good = 6 | 26.2% |
| | | Excellent = 7 | 6.7% | | Excellent = 7 | 23.8% |
| | | **Mean** | **4.4** | | **Mean** | **5.43** |
| **Books** | | Very Poor = 1 | 2.1% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 0.0% | | Poor = 2 | 0.9% |
| | | Below Average = 3 | 2.1% | | Below Average = 3 | 3.8% |
| | 47 | Average = 4 | 34.0% | 106 | Average = 4 | 4.7% |
| | | Good = 5 | 34.0% | | Good = 5 | 28.3% |
| | | Very Good = 6 | 17.0% | | Very Good = 6 | 28.3% |
| | | Excellent = 7 | 10.6% | | Excellent = 7 | 34.0% |
| | | **Mean** | **4.91** | | **Mean** | **5.81** |

**Table 16 Continued**

| Sources | N | Physician | | N | Patient | |
|---|---|---|---|---|---|---|
| **Medical Journals** | | Very Poor = 1 | 2.5% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 0.0% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 0.0% | | Below Average = 3 | 1.9% |
| | 40 | Average = 4 | 5.0% | 53 | Average = 4 | 9.4% |
| | | Good = 5 | 17.5% | | Good = 5 | 17.0% |
| | | Very Good = 6 | 45.0% | | Very Good = 6 | 37.7% |
| | | Excellent = 7 | 30.0% | | Excellent = 7 | 34.0% |
| | | **Mean** | **5.9** | | **Mean** | **5.92** |
| **Internet or Medical Websites** | | Very Poor = 1 | 2.0% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 2.0% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 3.9% | | Below Average = 3 | 2.2% |
| | 51 | Average = 4 | 27.5% | 90 | Average = 4 | 11.1% |
| | | Good = 5 | 29.4% | | Good = 5 | 30.0% |
| | | Very Good = 6 | 27.5% | | Very Good = 6 | 20.0% |
| | | Excellent = 7 | 7.8% | | Excellent = 7 | 36.7% |
| | | **Mean** | **4.94** | | **Mean** | **5.78** |
| **Telephone or Helpline** | | Very Poor = 1 | 6.5% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 3.2% | | Poor = 2 | 9.1% |
| | | Below Average = 3 | 19.4% | | Below Average = 3 | 0.0% |
| | 31 | Average = 4 | 19.4% | 11 | Average = 4 | 9.1% |
| | | Good = 5 | 35.5% | | Good = 5 | 18.2% |
| | | Very Good = 6 | 9.7% | | Very Good = 6 | 27.3% |
| | | Excellent = 7 | 6.5% | | Excellent = 7 | 36.4% |
| | | **Mean** | **4.29** | | **Mean** | **5.64** |

**Table 16 Continued**

| Sources | N | Physician | | N | Patient | |
|---|---|---|---|---|---|---|
| **TV/Radio** | | Very Poor = 1 | 7.7% | | Very Poor = 1 | 5.2% |
| | | Poor = 2 | 11.5% | | Poor = 2 | 6.9% |
| | | Below Average = 3 | 26.9% | | Below Average = 3 | 8.6% |
| | 26 | Average = 4 | 30.8% | 58 | Average = 4 | 25.9% |
| | | Good = 5 | 7.7% | | Good = 5 | 24.1% |
| | | Very Good = 6 | 11.5% | | Very Good = 6 | 13.8% |
| | | Excellent = 7 | 3.8% | | Excellent = 7 | 15.5% |
| | | **Mean** | **3.69** | | **Mean** | **4.6** |
| **Newspapers/Magazines** | | Very Poor = 1 | 10.3% | | Very Poor = 1 | 2.5% |
| | | Poor = 2 | 13.8% | | Poor = 2 | 2.5% |
| | | Below Average = 3 | 20.7% | | Below Average = 3 | 8.9% |
| | 29 | Average = 4 | 27.6% | 79 | Average = 4 | 25.3% |
| | | Good = 5 | 13.8% | | Good = 5 | 27.8% |
| | | Very Good = 6 | 13.8% | | Very Good = 6 | 20.3% |
| | | Excellent = 7 | 0.0% | | Excellent = 7 | 12.7% |
| | | **Mean** | **3.62** | | **Mean** | **4.85** |
| **Audio/Video Tapes** | | Very Poor = 1 | 5.7% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 0.0% | | Poor = 2 | 0.0% |
| | | Below Average = 3 | 8.6% | | Below Average = 3 | 6.7% |
| | 35 | Average = 4 | 34.3% | 15 | Average = 4 | 20.0% |
| | | Good = 5 | 28.6% | | Good = 5 | 20.0% |
| | | Very Good = 6 | 8.6% | | Very Good = 6 | 40.0% |
| | | Excellent = 7 | 14.3% | | Excellent = 7 | 13.3% |
| | | **Mean** | **4.63** | | **Mean** | **5.33** |

**Table 16 Continued**

| Sources | N | Physician | | N | Patient | |
|---|---|---|---|---|---|---|
| **Films/Movies** | | Very Poor = 1 | 16.7% | | Very Poor = 1 | 0.0% |
| | | Poor = 2 | 22.2% | | Poor = 2 | 6.3% |
| | | Below Average = 3 | 16.7% | | Below Average = 3 | 0.0% |
| | 18 | Average = 4 | 16.7% | 16 | Average = 4 | 18.8% |
| | | Good = 5 | 16.7% | | Good = 5 | 18.8% |
| | | Very Good = 6 | 5.6% | | Very Good = 6 | 37.5% |
| | | Excellent = 7 | 5.6% | | Excellent = 7 | 18.8% |
| | | **Mean** | **3.33** | | **Mean** | **5.38** |

**Table 17: Predictors of Information Seeking Behavior (Patients') (Source: Chen Wang)**

| Source | Stage | Gender | *Age* | Race | Education |
|---|---|---|---|---|---|
| Talking with physician or physicians assistant | 0.303 | 0.249 | 0.225 | 0.047 | 0.069 |
| Talking with nurse/other health professionals | 0.623 | 0.474 | 0.079 | 0.071 | 0.186 |
| Talking with a support group | 0.173 | 0.526 | 0.183 | 0.002 | 0.582 |
| Talking with other patients | 0.989 | 0.107 | 0.045 | 0.482 | 0.022 |
| Talking with relatives/friends/acquaintances | 0.382 | 0.421 | 0.084 | 0.69 | 0.164 |
| Email from physician or physician's assistant | 0.799 | 0.327 | 0.379 | 0.40 | 0.275 |
| Email from nurse/other health professionals | 0.263 | 0.712 | 0.138 | 0.358 | 0.622 |
| Email/chat room with a support group | 0.920 | 0.538 | 0.130 | 0.079 | 0.585 |
| Email/chat room with other patients | 0.648 | 0.947 | 0.027 | 0.037 | 0.607 |
| Email from relatives/friends/acquaintances | 0.275 | 0.139 | 0.133 | 0.383 | 0.001 |
| Educational program by HMO/hospital | 0.98 | 0.645 | 0.266 | 0.005 | 0.014 |
| National/local medical information services | 0.006 | 0.044 | 0.646 | 0.082 | 0.090 |
| Medical leaflets/pamphlets | 0.395 | 0.002 | 0.015 | 0.135 | 0.038 |
| Narratives(written stories by other patients) | 0.864 | 0.136 | 0.023 | 0.212 | 0.072 |
| Books | 0.292 | 0.015 | 0.027 | 0.009 | 0.000 |
| Medical Journals | 0.272 | 0.010 | 0.700 | 0.012 | 0.003 |
| Internet/medical websites | 0.799 | 0.124 | 0.002 | 0.127 | 0.000 |
| Telephone/helpline | 0.901 | 0.694 | 0.896 | 0.000 | 0.342 |
| TV/radio | 0.261 | 0.196 | 0.784 | 0.036 | 0.848 |
| Newspaper/magazines | 0.027 | 0.213 | 0.497 | 0.031 | 0.059 |
| Audio/video tapes | 0.234 | 0.975 | 0.141 | 0.034 | 0.453 |
| Films/movies | 0.885 | 0.873 | 0.038 | 0.601 | 0.590 |

**Table 17 Continued**

| Source | Working Status | Household Income | Insurance Coverage | Computer Access |
|---|---|---|---|---|
| Talking with physician or physicians assistant | 0.500 | 0.070 | 0.797 | 0.173 |
| Talking with nurse/other health professionals | 0.438 | 0.094 | 0.593 | 0.028 |
| Talking with a support group | 0.333 | 0.421 | 0.631 | 0.394 |
| Talking with other patients | 0.060 | 0.177 | 0.942 | 0.001 |
| Talking with relatives/friends/acquaintances | 0.969 | 0.347 | 0.498 | 0.469 |
| Email from physician or physician's assistant | 0.412 | 0.101 | 0.574 | 0.097 |
| Email from nurse/other health professionals | 0.715 | 0.290 | 0.623 | 0.070 |
| Email/chat room with a support group | 0.829 | 0.764 | 0.665 | 0.112 |
| Email/chat room with other patients | 0.865 | 0.378 | 0.714 | 0.282 |
| Email from relatives/friends/acquaintances | 0.525 | 0.012 | 0.399 | 0.000 |
| Educational program by HMO/hospital | 0.153 | 0.195 | 0.213 | 0.032 |
| National/local medical information services | 0.268 | 0.010 | 0.553 | 0.018 |
| Medical leaflets/pamphlets | 0.299 | 0.676 | 0.981 | 0.011 |
| Narratives(written stories by other patients) | 0.265 | 0.138 | 0.105 | 0.165 |
| Books | 0.000 | 0.143 | 0.981 | 0.105 |
| Medical Journals | 0.098 | 0.423 | 0.863 | 0.031 |
| Internet/medical websites | 0.001 | 0.151 | 0.537 | 0.000 |
| Telephone/helpline | 0.666 | 0.853 | 0.130 | 0.317 |
| TV/radio | 0.100 | 0.002 | 0.291 | 0.064 |
| Newspaper/magazines | 0.715 | 0.327 | 0.121 | 0.432 |
| Audio/video tapes | 0.386 | 0.582 | 0.541 | 0.289 |
| Films/movies | 0.104 | 0.126 | 0.256 | 0.492 |

**Table 18: Physicians Perspective of the Predictors of Information Seeking Behavior**

| Demographics | Yes (N=66) |
|---|---|
| Do you think stage is a predictor for patients' preference for sources of POMI? | 60.9% |
| Do you think gender is a predictor for patients' preference for sources of POMI? | 55.4% |
| Do you think age is a predictor for patients' preference for sources of POMI? | 89.2% |
| Do you think race is a predictor for patients' preference for sources of POMI? | 73.8% |
| Do you think education is a predictor for patients' preference for sources of POMI? | 98.5% |
| Do you think working status is a predictor for patients' preference for sources of POMI? | 80.0% |
| Do you think household income is a predictor for patients' preference for sources of POMI? | 76.9% |
| Do you think insurance coverage is a predictor for patients' preference for sources of POMI? | 36.9% |
| Do you think computer access is a predictor for patients' preference for sources of POMI? | 95.4% |

# CHAPTER VI

## DISCUSSION AND CONCLUSION

The objectives of this study were to identify the views of health care professionals on the patients' usage of various medical information sources, their evaluations of medical information quality, recommended medical information sources and difference in opinions with patient about the medical information sources. The results of the study contribute to understanding health care professionals' views of various medical information sources used by cancer patients. There were some interesting finds from these studies that have been discussed later in this chapter.

Several conclusions are supported by the data from this study. First, health care professionals reported current medical information sources (ranked by frequency) as human sources, printed media, organizational sources broadcast media, networked sources and other sources which is consistent only for "human sources" and "printed media" with Chen Wang's study and Informational Source Horizon Theory for general population (Savolainen et al., 2004). Even though both the groups prefer human sources and printed media as the most utilized sources, health care professionals were highly optimistic about the frequency of usage of human sources and printed media than compared to patients. Patients' frequency of utilization of human sources is 55.8% where as health care professionals expected it to be 89.7%. Similarly health care professionals expected 78.0% of the cancer patients to be utilizing print media to gather medical information, where as in reality only 39.7% of the patients reported using printed media. Since follow up questions were not asked in this study to identify the cause of difference in

perception of both the groups about the frequency of usage of medical information sources, future study conducted to investigate the cause can produce interesting results.

Second, for detailed source types it was not surprising that the top four most frequently used sources are all human sources. Consistent with previous studies, talking with physicians or physicians assistant and talking with nurse or other health professionals were reported as the top two medical information sources used by cancer patients in the past. The quality means of these two sources are 6.2 (6.22 by patients) and 5.62 (6.01 by patients), which were also among the top three among all the sources. These findings are consistent with previous studies that suggest that health professionals are the most trusted source for cancer information (Rutten etl al., 2004; Mills & Davidson, 2002; Kakai et al, 1999; O'Malley et al, 1999; Pennbridge et al, 1999; Cohn et al, 2003).

An interesting observation is that even though talking with relatives, friends and acquaintances has a mean quality of 2.68, health care professionals ranked it as the fourth most frequently used source by patients. The findings from my study support that for a majority number of medical information sources, healthcare professionals and patients have a different perception of the frequency of use by patients. Health care professionals always rated the mean quality of information from medical information sources lower than the patients for all the sources, especially for talking with relatives, friends and acquaintances (2.68 by physicians; 4.87 by patients) and, films and movies (2.51 by physicians; 5.08 by patients).

Another interesting finding is that even though health care professionals felt that they were the most frequently used source of cancer information, emails from health care professionals were ranked the lowest. This could be because health care professionals may not be finding sufficient time to correspond with the patients over email because of their busy schedule.

Third, health care professionals recommend medical information sources (ranked by frequency) as: organizational sources, human sources, printed media, other sources, networked sources and broadcast media which is totally inconsistent with the patients view of future sources of medical information from Chen Wang's study and Informational Source Horizon Theory for general population (Savolainen et al., 2004). Talking with physicians or physicians' assistant and talking with nurse or other health professionals were reported as the top two medical information sources. However, health care professionals rated only two human sources in the top four frequently used sources, where as patients rated all the top four frequently used sources as human sources, even though the mean quality of information expected from the other two human sources (talking with other patients and talking with friends/relatives/acquaintances) were ranked amongst the lowest by both the groups. An interesting observation is that health care professionals expect the mean quality of information from medical information sources to be lower than the patients expectations for all the sources, especially for films/movies (3.33 by physicians; 5.38 by patients) and email/chat room with other patients (3.9 by physicians; 6.67 by patients).

Health care professionals recommend that information gathered from other patients, relatives, friends and acquaintances either by talking or through email/chat room should be less frequently used and the quality of information is lower compared to other sources. However, patients rank these sources to be among the most frequently used for gathering medical information.

In general, health care professionals and patients view health professionals as the most the most trust source of medical information. However, there is a difference in opinion between both groups regarding majority the use and quality of other medical information sources.

Patients prefer to gather medical information sources from human sources, where as physicians recommend patients to make use of organizational sources and printed media. The results from this survey also indicate that health care professionals and patients have a different view of past and future medical information sources.

Fourth, health care professionals felt demographics of patients' influences patients' choice of medical information sources. More than 70% of the health care professionals felt that demographics including age, race, education, working status, household income and computer access influences patients' preference for medical information sources. These findings were consistent with Chen Wang's findings that age, education and computer access can be used as a predictor for medical information sources, but inconsistent for factors such as race, working status, gender, stage of cancer and household income of the patients. Therefore, the evidence from this study provides support that 1) certain patients' demographics can be used to determine the preference for the medical information sources (Galloway et al, 1997; Deridiarian, 1987; Bliss & Johnson, 1995; Bilodeau & Degner, 1996; Brandt, 1991) and 2) health care professionals and patients will have different perception about the predictors of the information seeking behavior.

This study has certain limitations. The sample size for this study was small (N=66) and thus may not be a good representation of the all health care professionals. Also, since majority of the participants in this study were oncologists (N=42), a bias in opinion could have been introduced.

Despite these shortcomings, this study is an indicator of health care professionals views the past and recommended medical information sources. However, further questions were not asked about why health care professionals recommended some sources over the other and what

they believe information can or cannot bring certain benefits such as reduction in anxiety. Future research needs to be done to investigate health care professionals view of the potential benefit of information on the cancer patients and why certain sources are recommend more frequently.

## APPENDIX A: QUESTIONNAIRE VERSION 1

**Medical Information Sources Inquiry for Cancer Patients**

The objective of this survey is to investigate the medical information sources you think patients have visited in the past and your recommendations to visit in the future, and the quality of the medical information that was obtained or expected from these sources.

# Part A: Background Information

All information will be kept confidential.

(Please check one box per question.)

| | | |
|---|---|---|
| 1 | **What type of cancer do you treat?**<br>☐ Bladder cancer<br>☐ Breast cancer<br>☐ Colon cancer<br>☐ Endometrial cancer<br>☐ Head and neck cancer<br>☐ Leukemia | ☐ Lung cancer<br>☐ Melanoma<br>☐ Non-Hodgkin's lymphoma<br>☐ Ovarian cancer<br>☐ Prostate cancer<br>☐ Rectal cancer<br>☐ *Other:* _____ |
| 2 | **Do you think choice for the source of information varies with the gender of the patient?** | ☐ Yes<br>☐ No<br>☐ NA |
| 3 | **Do you think choice for the source of information varies with the age of the patient?** | ☐ Yes<br>☐ No |
| 4 | **Do you think choice for the source of information varies with the educational qualification of the patient?** | ☐ Yes<br>☐ No |
| 5 | **Do you think choice for the source of information varies with the working status of the patient?** | ☐ Yes<br>☐ No |
| 6 | **Do you think choice for the source of information varies with the household income of the patient?** | ☐ Yes<br>☐ No |

## Part B: Medical Information Sources

All information will be kept confidential.

**EXAMPLE** Suppose you thought patients ***FOUND*** medical information both from books and TV/radio, and thought that the quality of information from Books was excellent but the information from TV/radio was poor, then you would check "Yes" for both, and circle "7" for the quality of information from Books and "1" for the quality of information from TV/radio;

| | Medical Information Sources | *Do* patients get Medical information from here? | If "Yes", how good is the information quality? Poor → Excellent |
|---|---|---|---|
| 16 | Books | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 19 | TV / radio | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |

Please check all that apply and circle the appropriate number.

| | Medical Information Sources | *Do* patients get Medical information from here? | If "Yes", how good is the information quality? Poor → Excellent |
|---|---|---|---|
| 1 | *Talking with physician or physician's assistant* | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 2 | E-mail from physician or physician's assistant | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 3 | Talking with physician's nurse / other health professionals in their office | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |

Please continue...

| | **Medical Information Sources** | *Section B1* | |
|---|---|---|---|
| | | *Do* patients get Medical information from here? | If "Yes", how good is the information quality? **Poor → Excellent** |
| 4 | E-mail from physician's nurse / other health professionals | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 5 | Attending educational program by HMO / hospital | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 6 | Talking with a support group | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 7 | E-mails from a support group | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 8 | Talking with other patients | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 9 | E-mails from other patients | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 10 | Narratives (written stories by other patients) | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 11 | Talking with relatives / friends / acquaintances | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 12 | E-mails from relatives / friends / acquaintances | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 13 | National / local medical information services *(e.g. National Institute of Health / National Cancer Institute)* | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 14 | Medical leaflets / pamphlets | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 15 | Medical journals / Medline / PubMed | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 16 | Books | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 17 | Internet medical web sites | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 18 | Telephone / helpline | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 19 | TV / radio | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 20 | Newspapers / magazines | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 21 | Audio / video tapes | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 22 | Films / movies | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |

## APPENDIX B: QUESTIONNAIRE VERSION 2

## MEDICAL INFORMATION SOURCES INQUIRY FOR CANCER PATIENTS

The objective of this survey is to investigate the medical information sources you think patients have visited in the past and your recommendations to visit in the future, and the quality of the medical information that was obtained or expected from these sources.

# Part A: Background Information

All information will be kept confidential.

(Please check one box per question.)

| | | |
|---|---|---|
| 1 | **What type of cancer do you treat?**<br>☐ Bladder cancer<br>☐ Breast cancer<br>☐ Colon cancer<br>☐ Endometrial cancer<br>☐ Head and neck cancer<br>☐ Leukemia | ☐ Lung cancer<br>☐ Melanoma<br>☐ Non-Hodgkin's lymphoma<br>☐ Ovarian cancer<br>☐ Prostate cancer<br>☐ Rectal cancer<br>☐ *Other:* _____ |
| 2 | **Do you think choice for the source of information varies with the gender of the patient?** | ☐ Yes<br>☐ No<br>☐ NA |
| 3 | **Do you think choice for the source of information varies with the age of the patient?** | ☐ Yes<br>☐ No |
| 4 | **Do you think choice for the source of information varies with the educational qualification of the patient?** | ☐ Yes<br>☐ No |
| 5 | **Do you think choice for the source of information varies with the working status of the patient?** | ☐ Yes<br>☐ No |
| 6 | **Do you think choice for the source of information varies with the household income of the patient?** | ☐ Yes<br>☐ No |

# Part B: Medical Information Sources

All information will be kept confidential.

**Section B1**

**EXAMPLE** Suppose you thought patients ***FOUND*** medical information both from books and TV/radio, and thought that the quality of information from Books was excellent but the information from TV/radio was poor, then you would check "Yes" for both, and circle "7" for the quality of information from Books and "1" for the quality of information from TV/radio;

| | **Medical Information Sources** | *Do* patients get Medical information from here? | *If "Yes", how good is* the information quality? **Poor → Excellent** |
|---|---|---|---|
| 16 | Books | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 19 | TV / radio | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |

Please check all that apply and circle the appropriate number.

| | **Medical Information Sources** | *Do* patients get Medical information from here? | If "Yes", how good is the information quality? **Poor → Excellent** |
|---|---|---|---|
| 1 | *Talking with physician or physician's assistant* | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 2 | E-mail from physician or physician's assistant | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 3 | Talking with physician's nurse / other health professionals in their office | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |

Please continue...

| | **Medical Information Sources** | *Section B1* | |
|---|---|---|---|
| | | *Do* patients get Medical information from here? | If "Yes", how good is the information quality? **Poor → Excellent** |
| 4 | E-mail from physician's nurse / other health professionals | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 5 | Attending educational program by HMO / hospital | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 6 | Talking with a support group | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 7 | E-mails from a support group | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 8 | Talking with other patients | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 9 | E-mails from other patients | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 10 | Narratives (written stories by other patients) | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 11 | Talking with relatives / friends / acquaintances | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 12 | E-mails from relatives / friends / acquaintances | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 13 | National / local medical information services *(e.g. National Institute of Health / National Cancer Institute)* | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 14 | Medical leaflets / pamphlets | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 15 | Medical journals / Medline / PubMed | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 16 | Books | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 17 | Internet medical web sites | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 18 | Telephone / helpline | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 19 | TV / radio | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 20 | Newspapers / magazines | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 21 | Audio / video tapes | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 22 | Films / movies | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |

**Section B2**

**EXAMPLE** Suppose you ***RECOMMEND*** patients to search for ***MORE*** medical information from Books but not from TV/radio, and expect that the quality of the information from Books to be excellent, then you would check "Yes" for Books and circle "7" for the quality of information from Books, and check "No" for TV/radio. Your answer would be like:

| | **Medical Information Sources** | *Do* you recommend patients to get Medical information from here? | *If "Yes", how good you expect* the information to be? **Poor → Excellent** |
|---|---|---|---|
| 16 | Books | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 19 | TV / radio | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |

Please check all that apply and circle the appropriate number.

| | **Medical Information Sources** | *Do* you recommend patients to get Medical information from here?? | *If "Yes", how good you expect* the information to be? **Poor → Excellent** |
|---|---|---|---|
| 1 | *Talking with physician or physician's assistant* | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 2 | E-mail from physician or physician's assistant | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 3 | Talking with physician's nurse / other health professionals in their office | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |

Please continue...

| | **Medical Information Sources** | *Section B1* | |
|---|---|---|---|
| | | *Do* you recommend patients to get Medical information from here? | *If "Yes", how good you expect* the information to be? **Poor → Excellent** |
| 4 | E-mail from physician's nurse / other health professionals | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 5 | Attending educational program by HMO / hospital | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 6 | Talking with a support group | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 7 | E-mails from a support group | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 8 | Talking with other patients | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 9 | E-mails from other patients | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 10 | Narratives (written stories by other patients) | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 11 | Talking with relatives / friends / acquaintances | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 12 | E-mails from relatives / friends / acquaintances | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 13 | National / local medical information services *(e.g. National Institute of Health / National Cancer Institute)* | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 14 | Medical leaflets / pamphlets | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 15 | Medical journals / Medline / PubMed | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 16 | Books | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 17 | Internet medical web sites | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 18 | Telephone / helpline | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 19 | TV / radio | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 20 | Newspapers / magazines | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 21 | Audio / video tapes | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 22 | Films / movies | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |

## APPENDIX C: QUESTIONNAIRE VERSION 3

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David Dilts, PhD, MBA
Professor & Director, Graduate Studies
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Vanderbilt University
Tel: 615-322-3479
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Dear Participant,

We are doing a study to investigate what oncologists, research nurses, and other care providers in oncology believe are sources of medical information for cancer patients and what they feel about the quality of such information. We also wish to investigate where care providers recommend cancer patients to go in the future for more information and what providers expect the quality of information to be from those sources.

Your responses to the survey will only be used for purpose of this study and not for any diagnostic or medical purposes. All individual responses are completely confidential. Completing the survey is entirely voluntary, and by doing so you consent to having the survey information used in the study.

The survey takes about **10-15 minutes**. There are three parts to the survey. The first part asks general background questions. The second part asks about sources of medical information. The third part presents you with four scenarios and asks your opinion of how likely you are to do something.

You may refuse to answer any question at any time and, again, all individual responses will be entirely confidential and anonymous.

This survey has been has been reviewed and received approval from the Institutional Review Board at Vanderbilt University. For questions concerning this study or survey, please contact Siddharth Rai at 615-322-7769, or Dr. David Dilts at 615-322-3479, or the Institutional Review Board at 615-322-2918 and 866-224-8273 (toll free).

Thank you very much for your time. Your input will help us to evaluate better ways to deliver health care information to patients.

Siddharth Rai
Management of Technology Program
Vanderbilt University

# Medical Information Sources Inquiry for Cancer Patients

## Instructions

Thanks for taking this survey. The objective of this survey is to investigate the medical information sources that you believe your patients have visited in the past and may visit in the future. Additional interest is your estimation of the quality of such medical information.

**Part A** In this part, we ask background information.
All individual responses will be kept completely confidential.

***Please answer the questions in this part by checking the appropriate box.***

**Part B** In this part, we will investigate the medical information sources you've visited in the past and will visit in the future through two sections: Section B1 and B2.

**Section B1** asks about the medical information sources patients have visited in past;

**Section B2** asks about the medical information sources you recommend patients to visit in the future.

***Please answer the questions in this part by checking the appropriate box***

## **Part A: Background Information.** All information will be kept confidential.

(Please check one box per question.)

| | | |
|---|---|---|
| 1 | **What type of cancer do you treat most frequently?**<br>☐ Bladder cancer<br>☐ Breast cancer<br>☐ Colon cancer<br>☐ Endometrial cancer<br>☐ Head and neck cancer<br>☐ Leukemia | ☐ Lung cancer<br>☐ Melanoma<br>☐ Non-Hodgkin's lymphoma<br>☐ Ovarian cancer<br>☐ Prostate cancer<br>☐ Rectal cancer<br>☐ *Other:* _____ |
| 2 | **Do you believe choice for the source of information varies with the gender of the patient?** | ☐ Yes<br>☐ No<br>☐ NA |
| 3 | **Do you believe choice for the source of information varies with the race of the patient?** | ☐ Yes<br>☐ No |
| 4 | **Do you believe choice for the source of information varies with the educational qualification of the patient?** | ☐ Yes<br>☐ No |
| 5 | **Do you believe choice for the source of information varies with the working status of the patient?** | ☐ Yes<br>☐ No |
| 6 | **Do you believe choice for the source of information varies with the household income of the patient?** | ☐ Yes<br>☐ No |

## Medical Information Sources All information will be kept confidential.

**EXAMPLE** Suppose you believe patients ***FOUND*** medical information both from books and TV/radio, and believe that the quality of information from Books was excellent but the information from TV/radio was poor, then you would check "Yes" for both, and circle "7" for the quality of information from Books and "1" for the quality of information from TV/radio; Suppose you ***RECOMMEND*** patients to search for ***MORE*** medical information from Books but not from TV/radio, and expect that the quality of the information from Books to be excellent, then you would check "Yes" for Books and circle "7" for the quality of information from Books, and check "No" for TV/radio. Your answer would be like:

| | Medical Information Sources | Section B1 | | Section B2 | |
|---|---|---|---|---|---|
| | | *Do* patients get Medical information from here? | *If "Yes", how good is* the information quality? (Very Poor → Excellent) | *Do* you recommend patients to get Medical information from here? | If "Yes", how good do you expect the information to be? (Very Poor → Excellent) |
| 16 | Books | ☐ Yes ☐ No | 1 2 3 4 5 6 7 | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 19 | TV / radio | ☐ Yes ☐ No | 1 2 3 4 5 6 7 | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |

Please check all that apply and circle the appropriate number

Medical information sources in Section B1

Quality Scale
**1 = Very Poor**
**2 = Poor**
**3 = Below Average**
**4 = Average**
**5 = Good**
**6 = Very Good**

Medical information sources in Section B2

| | Medical Information Sources | *Do* patients get Medical information from here? | If "Yes", how good is the information quality? (Very Poor → Excellent) | Do you recommend patients to get Medical information from here? | If "Yes", how good do you expect the information to be? (Very Poor → Excellent) |
|---|---|---|---|---|---|
| 1 | *Talking with physician or physician's assistant* | ☐ Yes ☐ No | 1 2 3 4 5 6 7 | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 2 | E-mail from physician or physician's assistant | ☐ Yes ☐ No | 1 2 3 4 5 6 7 | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |
| 3 | Talking with physician's nurse / other health professionals in their office | ☐ Yes ☐ No | 1 2 3 4 5 6 7 | ☐ Yes ☐ No | 1 2 3 4 5 6 7 |

| | Medical Information Sources | *Section B1* | | | Section B2 | | |
|---|---|---|---|---|---|---|---|
| | | *Do* patients get Medical information from here? | | If "Yes", how good is the information quality? | *Do* you recommend patients to Medical information from here? | | If "Yes", how good do you expect the information to be? |
| | | | | **Very Poor → Excellent** | | | **Very Poor → Excellent** |
| 4 | E-mail from physician's nurse / other health professionals | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 5 | Attending educational program by HMO / hospital | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 6 | Talking with a support group | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 7 | E-mails from a support group | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 8 | Talking with other patients | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 9 | E-mails from other patients | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 10 | Narratives (written stories by other patients) | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 11 | Talking with relatives / friends / acquaintances | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 12 | E-mails from relatives / friends / acquaintances | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 13 | National / local medical information services *(e.g. National Institute of Health / National Cancer Institute)* | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 14 | Medical leaflets / pamphlets | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 15 | Medical journals / Medline / PubMed | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 16 | Books | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 17 | Internet medical web sites | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 18 | Telephone / helpline | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 19 | TV / radio | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 20 | Newspapers / magazines | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 21 | Audio / video tapes | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |
| 22 | Films / movies | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 | ☐ Yes | ☐ No | 1 2 3 4 5 6 7 |

## APPENDIX D: FINAL QUESTIONNAIRE

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Tel: 615-322-7769

David Dilts, PhD, MBA
Professor & Director, Graduate Studies
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Vanderbilt University
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Dear Participant,

We are doing a study to investigate what oncologists, research nurses, and other care providers in oncology believe are sources of medical information for cancer patients and what they feel about the quality of such information. We also wish to investigate where care providers recommend cancer patients to go in the future for more information and what providers expect the quality of information to be from those sources.

Your responses to the survey will only be used for purpose of this study and not for any diagnostic or medical purposes. All individual responses are completely confidential. Completing the survey is entirely voluntary, and by doing so you consent to having the survey information used in the study.

The survey takes about **10-15 minutes**. There are three parts to the survey. The first part asks general background questions. The second part asks about sources of medical information. The third part presents you with four scenarios and asks your opinion of how likely you are to do something.

You may refuse to answer any question at any time and, again, all individual responses will be entirely confidential and anonymous.

This survey has been has been reviewed and received approval from the Institutional Review Board at Vanderbilt University. For questions concerning this study or survey, please contact Siddharth Rai at 615-322-7769, or Dr. David Dilts at 615-322-3479, or the Institutional Review Board at 615-322-2918 and 866-224-8273 (toll free).

Thank you very much for your time. Your input will help us to evaluate better ways to deliver health care information to patients.

Siddharth Rai
Management of Technology Program
Vanderbilt University

# Medical Information Sources for Patients

## Instructions

Thanks for taking this survey. The objective of this survey is to investigate the medical information sources that you believe your patients have visited in the past and may visit in the future. Additional interest is your estimation of the quality of such medical information.

**Part A** In this part, we ask background information.
All individual responses will be kept completely confidential.

***Please answer the questions in this part by checking the appropriate box.***

**Part B** This part asks about the medical information sources, including those your patients have visited in the past and may visit in the future.

***Please answer the questions in this part by checking the appropriate box.***

**Part C** In this part, we ask four opinion questions about different medical situations and how you view each.

***Please answer the questions in this part by checking the appropriate box.***

## Part A: Background Information

All information will be kept confidential.

(Please check one box or circle one answer per question.)

1 **What is your position:**

☐ **oncologist** ☐ **oncology nurse** ☐ **research nurse**
☐ **data manager** ☐ **research administrator** ☐ **other**

2 **What is your gender?** ☐ Male ☐ Female

3 **What is your age (in years)?** _____

4 **How many years have you been practicing?**

5 ***Do you use Internet to gather medical information?*** ☐ *Yes* ☐ *No*

6 **What type of cancer do you treat *most frequently*?**

☐ Bladder ☐ Endometrial ☐ Ovarian ☐ Brain
☐ Head/Neck ☐ Prostate ☐ Breast ☐ Leukemia
☐ Rectal ☐ Colon ☐ Lung ☐ Non-Hodgkin's lymphoma
☐ Melanoma ☐ *Other:* _____

7 **What would best describe the geographic location of your practice setting?**

☐ Urban area
☐ Metropolitan area
☐ Urban underserved area
☐ Counties outside of a metropolitan statistical area
☐ Rural health professional shortage area

8 **What would best describe your practice setting?**

☐ Solo practitioner's office
☐ Free- standing clinic
☐ **Group office**
☐ Medical School
☐ HMO
☐ Hospital
☐ Nursing Home/ Extended Care
☐ *Other :*

9 **In your practice, do you believe that where patients obtain medical information varies by the following *patient characteristics*:**

| | | |
|---|---|---|
| a. Gender | ☐ Yes | ☐ No |
| b. Age | ☐ Yes | ☐ No |
| c. Race | ☐ Yes | ☐ No |
| d. Educational level (years of schooling) | ☐ Yes | ☐ No |
| e. Working status / Occupation | ☐ Yes | ☐ No |
| f. Household income | ☐ Yes | ☐ No |
| g. Computer Access/Use | ☐ Yes | ☐ No |
| h. Insurance Coverage | ☐ Yes | ☐ No |
| i. General Health Condition | ☐ Yes | ☐ No |

10 (*Opinion question)* **From a range of not at all important *[1]* to critically important *[7]*, Do you believe the years of experience of a physician should influence a patient's choice of taking a recommended treatment?** *(Please circle one)*

*not at all important [ 1…2…3…4…5…6…7 ]critical to the choice*

11 (*Opinion question)* **From a range of not at all important *[1]* to critically important *[7]*, Do you believe the years a pharmaceutical firm has manufactured a drug should influence a patient's choice of a drug?** *(Please circle one)*

*not at all important [ 1…2…3…4…5…6…7 ]critical to the choice*

## Part B: Medical Information Sources

All information will be kept confidential.

**Section B**

There are a number of sources of medical information. For example, a patient could have heard something on TV or could have searched the Internet. We are interested in your opinion of each source, so each has a separate question.

There are four elements to each question in this section:

1. **Has** your typical patient used the specific source for medical information in the **past**?
2. What is your opinion of the quality of the information found from this source in the **past**?
3. **Will** you recommend the use of this medical source for information in the **future**?
4. What is your opinion of the expected quality of the information gathered from this source in the **future?**

**EXAMPLE**

**1.** Suppose you believe your typical patient has **FOUND** medical information from *Books* in the past and you believe that the quality of information from *Books* was excellent. You should check "Yes" in ***"PAST"*** column, and circle "7" the quality of information. Suppose you **WILL** recommend the use of *Books* as a source of information in the future and you expect that the quality of information will continue to be excellent. You should check "Yes" in ***"FUTURE"*** column and circle "7" for quality of information.

**2.** Suppose you believe your typical patient has **FOUND** medical information *TV/radio* and believe that the quality of information from *TV/radio* was poor, then in ***"PAST"*** column you would check "Yes" and circle "1". Suppose you **WILL not** recommend medical information from *TV/radio*, then you should leave "***FUTURE***" column (both the check box and the quality of information scale) blank.

Medical information sources in the ***PAST***

**Quality Scale**
**1 = Very Poor**
**2 = Poor**
**3 = Below Average**
**4 = Average**
**5 = Good**
**6 = Very Good**
**7 = Excellent**

Medical information sources in the ***FUTURE***

| | Medical Information Sources | PAST: *Do* patients get Medical information from | PAST: If "Yes", how good was the information quality? Very Poor → Excellent | FUTURE: *Will* you recommend medical information from | FUTURE: If "Yes", how good do you expect the information to be? Very Poor → Excellent |
|---|---|---|---|---|---|
| 1 | Books | ☒ Yes | 1…2…3…4…5…6…7 | ☒ Yes | 1…2…3…4…5…6…7 |
| 2 | TV/radio | ☒ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |

Medical information sources in the ***PAST***

**Quality Scale**
**1 = Very Poor**
**2 = Poor**
**3 = Below Average**
**4 = Average**
**5 = Good**
**6 = Very Good**
**7 = Excellent**

Medical information sources in the ***FUTURE***

| | Medical Information Sources | PAST | | FUTURE | |
|---|---|---|---|---|---|
| | | *Do* patients get Medical information from | If "Yes", how good was the information quality? **Very Poor → Excellent** | *Will* you recommend Medical information from | If "Yes", how good do you expect the information quality? **Very Poor → Excellent** |
| 1 | Talking with physician or physician's assistant | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 2 | Talking with nurse/other health professionals | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 3 | Talking with a support group | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 4 | Talking with other patients | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 5 | Talking with relatives/friends/acquaintances | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 6 | E-mail from physician or physician's assistant | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 7 | E-mail from nurse/other health professionals | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 8 | E-mail/Chat-room with a support group | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 9 | E-mail/Chat-room with other patients | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 10 | E-mails from relatives/friends/acquaintances | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 11 | Educational programs by HMO/hospital | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 12 | National/local medical information services (NIH/NCI) | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 13 | Medical leaflets/pamphlets | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 14 | Narratives (written stories by other patients) | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 15 | Books | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 16 | Medical journals | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 17 | Internet/medical websites | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 18 | Telephone/helpline | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 19 | TV/radio | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 20 | Newspapers/magazines | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 21 | Audio/video tapes | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |
| 22 | Films/movies | ☐ Yes | 1…2…3…4…5…6…7 | ☐ Yes | 1…2…3…4…5…6…7 |

## Part C: Medical Scenarios

All information will be kept confidential.

In this section, there are a number of different scenarios. Please read each scenario and then circle the value that most closely fits **your** likeliness of making the choice. Use the following likelihood scale:

**Likelihood Scale**

*1* **Extremely Unlikely**
*2* **Very Unlikely**
*3* **Unlikely**
*4* **Indifferent**
*5* **Likely**
*6* **Very Likely**
*7* **Extremely Likely**

**For example,** if you are indifferent to the choice in the scenario you would circle 4. If, on the other hand it is extremely likely that you chose the option, you would circle 7.

**Scenario 1:** Assume you wear glasses, but they are bothering you and are considering LASIK (Laser in Situ Keratomileusis) surgery. Searching the Internet using Google, you discover 332,000 "hits" on side effects and 31,500 "hits" on advantages. Searching Medline (a medical database containing journal articles physician use), you discover 13 articles on side effects and 637 articles on advantages of LASIK. **How likely are you to have LASIK surgery?**

*Extremely Unlikely [ 1…2…3…4…5…6…7 ] Extremely Likely*

**Scenario 2:** You have gone to your 60-year-old physician, who you have gone to all your life, for chronic back pain. She has suggested that you have lower back surgery. When searching the Internet for more information, you discover that surgery is not often done for low back pain because, in most cases, the cause of the pain cannot be helped by surgery (source: webMD.com).

**How likely are you to follow the surgery recommendation?**

*Extremely Unlikely [ 1…2…3…4…5…6…7 ] Extremely Likely*

**Scenario 3:** You notice a strange growth on your arm. You are not too concerned, but you spend half a day looking it up in the medical library. Everything you read says there is nothing to be concerned about. However, when walking to class, a fellow student sees it and remarks that they had something just like it and that it was malignant.

**How likely are you to make a special appointment with your doctor about the growth?**

*Extremely Unlikely [ 1…2…3…4…5…6…7 ] Extremely Likely*

**Scenario 4:** You have been diagnosed with Irritable Bowel Syndrome. Your primary care physician has informed you that two well known gastroenterologists have recently started practice in a local hospital, Dr. Zeta and Dr. Phi. When visiting Dr. Zeta's office you are given a waiver to sign informing you that Dr. Zeta has no malpractice insurance and that you promise not to sue for any reason. Upon calling, you discover that Dr. Phi has insurance and does not require a waiver.

**How likely are you to use Dr. Zeta's services?**

*Extremely Unlikely [ 1…2…3…4…5…6…7 ] Extremely Likely*

# APPENDIX E: PROPOSAL SUBMITTED TO IRB

Principal Investigator: Siddharth Rai Version Date: 04/08/04
Study Title: Medical information sources for cancer patients- Oncologists perspective
Institution/Hospital: Vanderbilt Ingram Cancer Center and Conference

**Vanderbilt University Institutional Review Board**

## Request for Exemption

**1. Principal Investigator Information**

| | | | |
|---|---|---|---|
| First Name: Siddharth | Middle Initial: | Last Name: Rai | |
| Degree(s): ☐ Ed.D. ☐ J.D. ☐ M.D. ☐ Ph.D. ☐ R.N. ☒ Other, specify: M.S. | | | |
| Job Title: Graduate Student | | Affiliation: ☒ VU ☐ Stallworth ☐VA-TN Valley HS ☐ Other, specify: | |
| Department/Division: Management of Technology | | School/College: School of Engineering | |
| Campus Address: | | Zip+4: | |
| Campus Phone: 322-7769 | Fax: 322-7996 | Pager: | Email: siddharth.rai@vanderbilt.edu |
| **Complete if PI does not have campus address:** | | | |
| Address: 3416 Murphy Road, Apt C12 | | City: Nashville | |
| State: TN | Zip: 37203 | Phone: 615-319-7539 | |

**2. Faculty Advisor (complete if PI is a student, resident, or fellow)** ☐ **NA**

| | | | |
|---|---|---|---|
| Faculty Advisor's name: Dr. David M. Dilts | | Title: Director Graduate Studies MOT | |
| Department/Division: EECS | | School/College: Engineering | |
| Campus Address: Box 1518, Station B | | Zip+4: | |
| Campus Phone: 322-3479 | Fax: 322-7996 | Pager: | Email: david.dilts@vanderbilt.edu |

**3. Study Contact Information (complete if primary contact is different from PI)** ☐ **NA**

| | | | |
|---|---|---|---|
| First Name: | Middle Initial: | Last Name: | |
| Degree(s): ☐ Ed.D. ☐ J.D. ☐ M.D. ☐ Ph.D. ☐ R.N. ☐ Other, specify: | | | |
| Job Title: | | Affiliation: ☐ VU ☐ Stallworth ☐VA-TN Valley HS ☐ Other, specify: | |
| Department/Division: | | School/College: | |
| Campus Address: | | Zip+4: | |
| Campus Phone: | Fax: | Pager: | Email: |
| **Complete if contact does not have campus address:** | | | |
| Address: | | City: | |
| State: | Zip: | Phone: | |

**4. Study Information:**

A. Give a brief synopsis of the research, including background information and rationale.

Patients use various sources of health information to gain knowledge about their illness and prognosis, treatment options and side effects, ways to prevent recurrence, and psychological resources for coping (Cassileth et al, 1980; Fallowfield et al, 1994). The ability to clearly determine patients' potential medical information sources can help both physicians and patients to make more efficient communications and decisions together (Dranove, 1988; Labelle et al 1994; Kleffens et al 2003). Many studies about patient information sources have been done for diseases like heart failure (Gwadry-Sridhar et al, 2003) and AIDS (Reeves 2000). However, despite the extensive literature on information provision for patients with cancer, there are only a limited number of studies that have investigated the preferred sources of information for cancer patients (Mills et al 2002) and physician's belief about the sources from where cancer patients get medical information. Chen Wang's survey (*IRB#:* 040120)which has already been approved, investigated the medical information sources that cancer patients have visited in the past and prefer to visit in the future, and the quality of the medical information they thought or expect from those sources. My survey will investigate healthcare professional's belief about the medical information sources that cancer patients have visited in the past and medical information sources they recommend patients to visit in the future and the quality of the medical information they thought or expect from those sources. There are two parts in this survey: Part A,

Part B. Part A investigates some background information. Part B investigates oncologists, research nurses and other care providers' belief about the medical information sources patients have visited in the past and where care providers recommend to patients to visit in the future (Please see the attached questionnaire and question citation list).

B. Describe the subject population/ type of data/specimens to be studied. Note: Research involving prisoners, fetuses, pregnant women, non-viable neonates, or human in vitro fertilization are not eligible for exemption from IRB review.

The subject population will be practicing oncologists at Vanderbilt Ingram Cancer Center and oncologists participating in the American Society of Clinical Oncology (ASCO) annual meeting to be held in New Orleans, during June 5-8, 2004. Emails will be sent to all the oncologists at Vanderbilt Ingram Cancer Center (VICC) and all the members of ASCO requesting their permission for participation. There is no risk for them to answer the questionnaire. The type of data is mainly qualitative, not linked to specific individuals. There are no identifiers on the survey and none will be collected. Questionnaires will be given to the care providers at the conference.

C. Describe the source of data/specimens and if these are publicly available. If not publicly available, describe how prior approval will be obtained before accessing this information (attach approval letter if available).

VICC- Email will be send to the oncologists which will introduce investigators to the participants, present the information letter, and describe the study. Oncologists will be asked if they are interested in participating. Survey would be send to only those oncologists who give approval for their participation in the study.

ASCO - Dr. David Dilts, Ph.D. is a member of ASCO and he has two different presentations to make during the ASCO annual meeting. We will send an Email in advance to all the members of the conference that Dr. Dilts will be attending, introducing investigators to the participants, present the information letter, and describe the study. Questionnaires will be given to the interested oncologists at ASCO annual meeting. Survey would be given to only those oncologists who will be interested in participating

D. Does this study involve the collection of existing records or data often referred to as "on-the-shelf" data [see 45 CFR 46.101 (b)(4)]? Describe how this data is collected, stored and de-identified.

No.

E. Describe the recruitment process, including any advertisements, to be used for this study.

The participants will be recruited from the list of physicians at (VICC) and care providers at the conference with inclusion criteria including: 1) oncologists, research nurses and other care providers; 2) should be treating cancer patients above the age of 18 years.

F. Describe any procedures to be used during this study.

Investigators will introduce themselves to participants, present the information letter, and describe the study using Email. Oncologists, research nurses and other care providers will be asked if they are interested in participating. If they agree to participate, he/she will be asked complete the questionnaire. Participant will be informed that the information will be kept confidential. After the questionnaire is completed, investigators will confirm that the information collected has no identifying information. Participants are then thanked for their participating in this study.

G. Is this study affiliated with any other IRB-approved studies?

☐ No ☒ Yes

*If "Yes", please list by IRB#:* 040120 Chen Wang's study about "Medical information sources for cancer patients," which has been approved by IRB.

H. Is this proposal associated with a grant or contract?

☒ No ☐ Yes

*If "Yes", attach copy and list the funding source associated with the grant or contract.*

**CATEGORIES OF EXEMPTION**

Involvement of human subject research in the following categories may be declared exempt from IRB Review by the IRB. Only the IRB may determine which activities qualify for an exempt review. From the six categories presented below, check "**Yes**" for the categories that you believe describe your proposed research and "**No**" for all others. If none of the categories apply, complete an application for expedited or standard IRB review or contact the IRB staff for instructions.

**YOU MUST CHECK "YES" OR "NO" FOR ALL OF THE FOLLOWING:**

**45 CFR 46.101(b)(1):**

☐ Yes ☒ No **EVALUATION/COMPARISON OF INSTRUCTIONAL STRATEGIES/CURRICULA**

Research conducted in established or commonly accepted educational settings, involving normal educational practices, such as (i) research on regular and special education instructional strategies, or (ii) research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.

*If "Yes", describe the educational setting in which the research will be conducted and the type of normal educational practices involved.*

**45 CFR 46.101(b)(2):**

☒ Yes ☐ No **EDUCATIONAL TESTS, SURVEYS, INTERVIEWS, OR OBSERVATIONS**

Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

**Note: This exemption is not available for research involving children unless the research is limited to observation of public behavior when the investigators do not participate in the activities being observed.**

**45 CFR 46.101(b)(3):**

☐ Yes ☒ No **PUBLIC OFFICIALS OR CANDIDATES FOR PUBLIC OFFICE**

Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior that is not exempt under the previous paragraph if: (i) the human subjects are elected or appointed public officials or candidates for public office; or (ii) Federal statute(s) require(s) without exception that the confidentiality of the personally identifiable information will be maintained throughout the research and thereafter.

Describe how subjects may be identified or are at risk, or state the federal statute that allows the confidentiality of the subject to be maintained throughout the research and thereafter.

**45 CFR 46.101(b)(4):**

☐ Yes ☒ No **COLLECTION OR STUDY OF EXISTING DATA**

Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

**Note: To qualify for this exemption, the data, documents, records, or specimens must be in existence before the project begins. Additionally, under this exemption, an investigator (with proper authorization) may inspect identifiable records, but may only record**

**information in a non-identifiable manner. See IRB Policy III.D for additional information and examples regarding this exemption.**

**45 CFR 46.101(b)(5):**

☐ Yes ☒ No **RESEARCH & DEMONSTRATION PROJECTS**

Research and demonstration projects which are conducted by or subject to approval of federal Departmental or Agency heads (such as the Secretary of HHS), and which are designed to study, evaluate, or otherwise examine: (i) Public benefit or service programs; (ii) procedures for obtaining benefits or services under those programs; (iii) possible changes in or alternatives to those programs or procedures; (iv) possible changes in methods or levels of payment for benefits or services under those programs.

Proof of approval by Department/Agency Head is attached. ☐Yes ☐No

**Note: This exemption applies to federally funded projects only and is most appropriately invoked with authorization or concurrence from the funding agency. Additionally, specific criteria must be satisfied to invoke this exemption (see IRB Policy III.D). Also, this exemption category does not apply if there is a statutory requirement that this project be reviewed by an IRB or if the research involves physical invasion or intrusion upon the privacy of subjects.**

**45 CFR 46.101(b)(6):**

☐Yes ☒ No **FOOD QUALITY EVALUATION & CONSUMER ACCEPTANCE STUDIES**

Taste and food quality evaluation and consumer acceptance studies, (i) if wholesome food, without additives are consumed or (ii) if a food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the FDA or approved by the EPA or the Food Safety and Inspection Service of the U.S. Department of Agriculture.

**5.** Will Protected Health Information (PHI)[1] be accessed (used within VUMC) in the course of preparing for this research?

☒ No ☐ Yes

*If "No", skip to the Conflict of Interest statement on the next page.*

**STATEMENT OF AFFIRMATION**

**If Protected Health Information (PHI)[1] is accessed (used) in the course of preparing for this research the following 3 conditions must be met:**

1. The use or disclosure of the PHI is sought solely for the purpose of preparing this research protocol.
2. The PHI will not be removed from the covered entity.
3. This PHI is necessary for the purpose of this research study.

*The above 3 conditions must be met to allow for the access (use) of PHI as "preparatory to research."*

A. Will a de-identified data set be created *(all 18 HIPAA identifiers must be removed, see list attached)*?
☐ No ☐ Yes

B. Will a limited data set be created?
☐ No ☐ Yes *If "Yes", complete the VUMC "Data Use Agreement" below.*

*The data use agreement below sets forth the terms and conditions in which the Covered Entity (VUMC) will allow the use and disclosure of a limited data set [2] to the Data Recipient (Principal Investigator). The limited data set must have direct identifiers removed, but may include town, city, and/or 5-digit ZIP codes as well as date elements (e.g., dates of birth, admission, discharge, etc.).*

**VUMC DATA USE AGREEMENT** ☒ **NOT APPLICABLE**

In addition to the Principal Investigator, identify all individuals who will be requesting authorization to access the limited data set:

| **Name of Institution and/or Individual** | **Non-VUMC Data Use Agreement Required?*** |
|---|---|
| | ☐ Yes ☐ No |
| | ☐ Yes ☐ No |
| | ☐ Yes ☐ No |
| | ☐ Yes ☐ No |
| | ☐ Yes ☐ No |
| | ☐ Yes ☐ No |

**A Non-VUMC data use agreement is required to disclose the limited data set to an Individual or an Institution outside of VUMC. A template is available at:*
*http://www.mc.vanderbilt.edu/irb/Forms/Form1109DataUseAgreement.doc.*

**As the Principal Investigator of this study I agree:**

Not to use or disclose the limited data set for any purpose other than the research project or as required by law.

To use appropriate safeguards to prevent use or disclosure of the limited data set other than as provided for by this Agreement.

To report to the Covered Entity (Vanderbilt University Medical Center) any use or disclosure of the limited data set not provided for by this agreement, of which I become aware, including without limitation, any disclosure of PHI to an unauthorized subcontractor.

To ensure that any agent, including a subcontractor, to whom I provide the limited data set, agrees to the same restrictions and conditions that applies through this agreement to the Data Recipient with respect to such information.

Not to identify the information contained in the limited data set or contact the individual.

**Conflict of Interest Statement**

Do you or any other person responsible for the design, conduct, or reporting of the research have an economic interest in, or act as an officer or a director of any outside entity whose financial interests would reasonably appear to be affected by the research? ☐ Yes ☒ No

**Investigator Assurance and Compliance Statement**

As the PI of this study I agree:
☒ To accept responsibility for the scientific and ethical conduct of this project;
☒ To ensure all investigators and key study personnel have completed the VU human subjects training program;
☒ To submit for approval any additions, corrections or modifications to the protocol or informed consent document to the IRB prior to the implementation of any changes; and
☒ This project will not be started until final approval has been granted from the IRB.

Principal Investigator: Siddharth R. Version Date: 04/08/04
Study Title: Medical information sources for cancer patients- Oncologists Perspective
Institution/Hospital: Vanderbilt Ingram Cancer Center

Siddharth Rai 04/12/04
Principal Investigator's Signature Date

Faculty Advisor (if PI is non-faculty) 4/12/2004
Date

Request for Exemption (Form #1102)
Form Revision Date: 08/06/2003

[1] **Protected Health Information (PHI):** Protected health information (PHI) is individually identifiable health information that is or has been collected or maintained by Vanderbilt University Medical Center, including information that is collected for research purposes only, and can be linked back to the individual participant. Use or disclosure of such information must follow HIPAA guidelines.

Individually identifiable health information is defined as any information collected from an individual (including demographics) that is created or received by a health care provider, health plan, employer, and/or health care clearinghouse that relates to the past, present or future physical or mental health or condition of an individual, or the provision of health care to an individual or the past, present or future payment for the provision of health care to an individual and identifies the individual and/or to which there is reasonable basis to believe that the information can be used to identify the individual **(45 CFR 160.103).**

A covered entity (VUMC) may determine that health information is not individually identifiable (**De-identified**) health information only if all of the following identifiers of the individual or of relatives, employers, or household members of the individual are removed:

1. Names;
2. Any geographic subdivisions smaller than a State, including street address, city, county, precinct, zip code, and their equivalent geocodes, except for the initial three digits of a zip code;
3. All elements of dates (except year) for dates directly related to an individual (e.g., date of birth, admission);
4. Telephone numbers;
5. Fax numbers;
6. Electronic mail addresses;
7. Social security numbers;
8. Medical record numbers;
9. Health plan beneficiary numbers;
10. Account numbers;
11. Certificate/license numbers;
12. Vehicle identifiers and serial numbers, including license plate numbers;
13. Device identifiers and serial numbers;
14. Web Universal Resource Locators (URLs);
15. Internet Protocol (IP) address numbers;
16. Biometric identifiers, including finger and voiceprints;
17. Full-face photographic images and any comparable images; and
18. Any other unique identifying number, characteristic, or code.

[2] **Limited data set:** The limited data set is protected health information that **excludes** all above data elements with the exception of elements of dates, geographic information (not as specific as street address), and any other unique identifying element not explicitly excluded in the list above.

# APPENDIX F: APPROVAL LETTER FROM IRB

Vanderbilt University
Institutional Review Board
D-3232 Medical Center North Nashville, Tennessee 37232-2598
(615) 322-2918 Fax: (615) 343-2648
www.mc.vanderbilt.edu/irb

April 16, 2004

Siddharth Rai
511 Chesterfield Ave. Apt. 9A
Nashville, TN 37212

David M. Dilts, Ph.D.
Management of Technology
Box 1518, Sta. B.
Nashville, TN

**RE: IRB# 040295 "Medical Information Sources for Cancer Patients-Oncologist Perspective"**

Dear Mr. Rai,

A designee of the Institutional Review Board reviewed the Request for Exemption application identified above. The designee determined the study poses minimal risk to participants. This study meets 45 CFR 46.101 (b) category (2) for Exempt Review.

Exempt studies do not need complete annual reviews, however, any changes to the research proposal must be presented to the IRB for approval before implementation.

**DATE OF IRB APPROVAL: April 16, 2004**

Sincerely,

Eugene A. Gallagher, M.S.P.H., CIM, CIP
Institutional Review Board
Behavioral Sciences

## BIBLOGRAPHY


ACS (American Cancer Society). (2004b). What is cancer? Available at http://www.cancer.org [2004, Nov 05].

ACS (American Cancer Society). (2004a). Cancer Facts & Figures 2004. Available at: http://www.cancer.org [2004, Nov 05].

Arora NK (2003). Interacting with cancer patients: the significance of physicians' communication behavior. *Social Science & Medicine*; 57: 791–806.

Ashbury FD, Findlay H, Reynolds B & McKerracher K (1998). A Canadian Survey of Cancer Patients' Experiences: Are Their Needs Being Met? *Journal of Pain and Symptom Management*; 16(5): 298-306.

Baird J. Encouraging Informed Patients: Towards Joint Decision Making, Roy Castle *Lung Cancer Foundation*.

Bakker DA, Fitch MI, Gray R, Reed E & Bennett J (2001). Patient-health care provider communication during chemotherapy treatment:The perspectives of women with breast cancer. *Patient Education and Counseling*; 43: 61–71.

Balmer C (2005). The information requirements of people with cancer: where to go after the "patient information leaflet". *Cancer Nurs.;* 28(1), 36-44.

Basch EM, Thaler HT, Shi W, Yakren S & Schrag D (2004). Use of information resources by patients with cancer and their companions. *American Cancer Society*. Available at: www.interscience.wiley.com [2004, May 3]

Beaver K, Bogg J & Luker KA (1999). Decision-making role preferences and information needs: a comparison of colorectal and breast cancer. *Health Expect* ; 2 : 266-276.

Bilodeau BA and Degner LF (1996). Informational needs, sources of information and decisional roles in women with breast cancer. *Oncol Nurs Forum*; 23(4), 691-696.

Carlsson M (2000). Cancer patients seeking information from sources outside the health care system. *Support Care Cancer*; 8(6): 453–457.

Cassileth BR, Zupkis RV, Sutton-Smith K, March V (1980). Information and participation preferences among cancer patients. *Ann Intern Med*; 92:832–836.

Chaitchik S, Kreitler S, Shaked S, Schwartz I, & Rosin R (1992). Doctor-patient communication in a cancer ward. *Journal of Cancer Education*; 7: 41–54.

Charles C, & DeMaio S (1993). Lay participation in health care decision making: A conceptual framework. *Journal of Health Politics Policy, and Law*; 18: 881–904.

Charles C, Gafnv A & Whelan T (1997). Shared decision making in the medical encounter; what does it mean? (Or it takes at least two to tango). *Social Science & Medicine*; 44(5): 681-692.

Charles C, Gafni A, Whelan T (1999). Decision-making in the physician-patient encounter:revisiting the shared treatment decision-making model. *Social Science & Medicine*; 49: 651-661.

Chen X & Siu LL (2001). Impact of the Media and the Internet on Oncology: Survey of Cancer Patients and Oncologists in Canada. *Journal of Clinical Oncology*; 19(23): 4291-4297.

Climent J (1999). US Senate passes patients' bill of rights (news). *British Medical Journal*, 319, 209.

Cohn, Wendy F.; Ropka, Mary E.; Jones, Susan M.; Miesfeldt, Susan. (2003). Information needs about hereditary breast cancer among women with early-onset breast cancer. *Cancer Detection and Prevention*, Volume 27, Issue 5, 345-352.

Coley CM, Barry MJ, Mulley AG (1997). Early detection of prostate cancer. Clinical Guideline: Part III. *Ann Intern Med*;126:480–484.

Coulter A. (2003). Patient information and shared decision-making in cancer care. *Br J Cancer*; 89 Suppl. 1: S15-S16.

Derdiarian A. (1987). Informational needs of recently diagnosed cancer patients. Method and Description. Part 2. *Cancer Nurs*; 10(3): 156-163.

Diaz, Joseph A.; Griffith, Rebecca A., NG, James J.; Reinert, Steven E.; Friedmann, Peter D.; Moulton, Anne W. (2002). Patients' use of the Internet for medical information. *JGen Intern Med*, 17, 180-185.

Docherty A (2004). Experience, functions and benefits of a cancer support group. *Patient Education and Counseling*; 55: 87–93.

Edwards D. (1998). Head and neck cancer services: views of patients, their families and professionals. *British journal of oral and maxillofacial surgeons*; 36: 99-102.

Eidea H, Graugaarda P, Holgersena K & Finset A(2003). Physician communication in different phases of a consultation at an oncology outpatient clinic related to patient satisfaction. *Patient Education and Counseling*; 51: 259-266.

Elliott B & Elliott G (2000). High volume medical web sites. *Delaware Medical Journal*; 72(1): 21–29.

Elwyn G, Edwards A, Mowle S, Wensing M, Wilkinson C, Kinnersley P & Grol R (2001). Measuring the involvement of patients in shared decision making: a systematic review of instruments. *Patient Education and Counseling*; 43: 5-22.

Emanuel EJ and Emanuel LL (1992). Four models of the physician-patient relationship. *Journal of the American Medical Association*; 267, 2221.

Entwistle VA, Watt IS, Gilhooly K, Buggea C, Haites N & Walker AE (2004). Assessing patients' participation and quality of decision-making: insights from a study of routine practice in diverse settings. *Patient Education and Counseling*; 55: 105–113.

Fallowfield L, Ford S, Lewis S (1994). Information preference of patients with cancer. *Lancet*; 344,1576

Feldman-Stewart D & Brundage MD (2004). Challenges for designing and implementing decision aids. *Patient Education and Counseling*; 54: 265–273.

Ferguson T(2002). From patients to end users. *BMJ;* 324(7337), 555-556.

Ford S, Fallowfield L & Lewis S (1996). Doctor–patient interactions in oncology. *Social Science & Medicine*; 42: 1511–1519.

Ford A, Fallowfield L, Lewis S (1994). Can oncologists detect distress in their out-patients and how satisfied are they with their performance during bad news consultations? *Breast J Cancer*; 709:767–770.

Fox S & Rainee L (2000). The online health care revolution: how the Web helps Americans take better care of themselves. Washington, DC: *Pew Internet &American Life Project*. Available at: http://www.pewinternet.org/reports [2003, July 16]

Fox, Susannah; and Fallows, Deborah. (2003). Internet Health Resources. *Pew Internet & American Life Project*. Available at: http://www.pewinternet.org/reports [2003, July 16]

Frosch DL & Kaplan RM (1999). Shared Decision Making in Clinical Medicine: Past Research and Future Directions. *American Journal of Preventive Medicine*; 17(4):285–294.

Gagliardi A & Jadad AR (2002). Examination of instruments used to rate quality of health information on the internet: chronicle of a voyage with an unclear destination. *BMJ*; 324 (7337) : 569-573.

Galloway S, Graydon J, Harrison D, Evans-Boyden B, Palmer-Wickham S, Burlein-Hall S, Rich-van der Bij L, West P, Blair A (1997) Informational needs of women with a recent diagnosis of breast cancer: development and initial testing of a tool. *Journal of Advanced Nursing*; 25: 1175–1183.

Gattellaria M, Butowa PN, Tattersall MHN (2001). Sharing decisions in cancer care. *Social Science & Medicine*; 52: 1865–1878.

General Medical Council (1993). Tomorrow's Doctors: Recommendations on Undergraduate Medical Education. *General Medical Council, London*.

Godolphin W, Towle A & McKendry R (2001) Evaluation of the quality of patient information to support informed shared decision-making. *Health Expectations*; 4: 235-242.

Guidry JJ, Aday LA, Zhang D, & Winn RJ (1998). Information sources and barriers to cancer treatment by racial/ethnic minority status of patients. *Journal of Cancer Education*; 13(1): 43–48.

Gwyna R &Elwyn G (1999). When is a shared decision not (quite) a shared decision? Negotiating preferences in a general practice encounter. *Social Science & Medicine*; 49:437-447

Hack TF, Degner LF, Dyck DG (1994). Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis. *Social Science and Medicine*; 39(2): 279–289

Haidet P, Hamel MB, Davis RB, Wenger N, Reding D, Kussin PS, Connors AF, Lynn J, Weeks JC & Phillips RS (1998). Outcomes, Preferences for Resuscitation, and Physician-Patient Communication among Patients with Metastatic Colorectal Cancer. *The American Journal of Medicine*; 105:222–229.

Hann DM, Baker F & Denniston MM (2003). Oncology professionals' communication with cancer patients about complementary therapy: a survey. *Complementary Therapies in Medicine*; 11: 184–190.

Hanneke de Haes & Koedoot N (2003). Patient centered decision making in palliative cancer treatment: a world of paradoxes. *Patient Education and Counseling*; 50: 43–49.

Helft PR, Hlubocky F, & Daugherty CK (2003). American Oncologists' Views of Internet Use by Cancer Patients: A Mail Survey of American Society of Clinical Oncology Members. *Journal of Clinical Oncology*; 21(5):942-947.

Hertzum M, Andersen HK, Andersen V & Hansen CB (2002). Trust in information sources: seeking information from people, documents, and virtual agents. *Interacting with Computers;*14(5),575-599.

Hoffman-Goetz L & Clarke JN (2000). Quality of breast cancer sites on the World Wide Web. *Can J Public Health*; 91, 281-284.

Horrigan, John; Lenhart, Amanda; Spooner, Tom; Burke, Maura; Lewis, Oliver; Carter, Cornelia. (2000). The online health care revolution: how the web helps Americans take better care of themselves. *Pew Internet & American Life Project*. Available at: http://www.pewinternet.org/reports [2000, November 26]

Hurley J, Birch S & Eyles J (1992). Information, efficiency and decentralization within health care systems. *CHEPA Working Paper* 92-21. McMaster University, Hamilton.

James C, James N, Davies D, Harvey P & Tweddle S (1999). Preferences for different sources of information about cancer. *Patient Education and Counseling*; 37: 273–282.

Jefford and Tattersall (2002). Informing and involving cancer patients in their own care. *Lancet Oncol*;3(10):629-37.

Jenkins V, Fallowfield L & Saul J (2001). Information needs of patients with cancer: results from a large study in UK cancer centers. *Br J Cancer;* 84(1): 48-51.

Johnson J. David; and Meischke H. (1991). Cancer information: women's source and content preferences. *J Health Care Marketing*, Volume 11, 37-44

Johnson, J. David; Andrews; James E.; and Allard, Suzie. (2001). A model for understanding and affecting cancer genetics information seeking. *Library & Information Science Research*, Volume 23, Issue 4, Winter, P335-349.

Junghans TB, Sevin IF, Ionin B & Seifried H (2004). Cancer information resources: digital and online sources. *Toxicology*; 198: 177–193.

Kahana E & Kahana B (2003). Patient proactivity enhancing doctor–patient–family communication in cancer prevention and care among the aged. *Patient Education and Counseling*; 50:67–73.

Kakai H, Maskarinec G, Shumay DM, Tatsumura Y, Tasaki K (2003). Ethnic differences in choices of health information by cancer patients using complementary and alternative medicine: an exploratory study with correspondence analysis. *Social Science & Medicine*; 56: 851–862

Kreps, G. L., & Kunimoto, E. N. (1994). Effective communication in multicultural health care settings. Thousand Oaks, CA: Sage.

Laine C, Davidoff F(1996). Patient-centered medicine: a professional evolution. *JAMA* ;275:152– 156.

Lauri S, Sainio C (1998) Developing the nursing care of breast cancer patients: an action research approach. *Journal of Clinical Nursing*; 7: 424–432

Leadbeater, Maria BA (Hons). (2001). Information needs of patients with cancer. *Nursing Standard*, Volume 16, Issue 3, October, P33-35.

Lelie A (2000). Decision-making in nephrology: shared decision making? *Patient Education and Counseling*; 39: 81–89.

Levine MN, Gafni A & Markham B (1992). A bedside decision instrument to elicit a patient's preference concerning adjuvant chemotherapy for breast cancer. *Annals of Internal Medicine*; 117: 53.

McCreadie, Maureen; and Rice, Ronald E. (1999). Trends in analyzing access to information. Part I: cross-disciplinary conceptualizations of access. *Information Processing and Management*, 35, P45-76.

McWilliam CL, Brown JB & Stewart M (2000). Breast cancer patients' experiences of patient–doctor communication: a working relationship. *Patient Education and Counseling*; 39:191–204.

Middleton RG, Thompson IM, Austenfeld MS, et al. (1995). Prostate Cancer Clinical Guidelines Panel: Report on the Management of Clinically Localized Prostate Cancer. Baltimore, MD: American Urological Association.

Mills M & Davidson R (2002). Cancer patients' sources of information: use and quality issues. *Psycho-Oncology* 11: 371–378.

Mills ME and Sullivan K (1999). The importance of information giving for patients newly diagnosed with cancer: a review of the literature. *J Clin Nurs*; 8:631-642.

Mills ME and Sullivan K (2000). Patients with operable esophageal cancer: their experience of information-giving in a regional thoracic unit. *J Clin Nurs*; 9, 236-246.

Mills ME & Davidson R (2002). Cancer patients' sources of information: use and quality issues. *Psycho-Oncology*; 11:371–378.

Mooney G & Ryan M(1993). Agency in health care: Getting beyond first principles. *Journal of Health Economics*; 12: 125.

Mossman J, Boudioni M & Slevin ML (1999). Cancer information: a cost-effective intervention. *European Journal of Cancer*, Volume 35, Issue 11, P1587-1591.

Nair MG, Hickok JT, Rosco JA & Morrow GR (2000). Sources of information used by patients to learn about chemotherapy side effects. *Journal of Cancer Education;* 15, 19-22.

National Institutes of Health Consensus Development Panel (1997). National Institutes of Health consensus development conference statement: Breast cancer screening for women ages 40–49. *J Natl Cancer Inst*;89,1015–1026

Nilsson-Ihrfelt E, Fjallskog M, Blomqvist C,Ahlgren J, Edlund P, Hansen J, Malmberg L, Villman K & Andersson G (2004). Breast cancer on the Internet: the quality of Swedish breast cancer websites. *The Breast*;13, 376–382

O'Malley AS, Kerner JF & Johnson L (1999). Are We Getting the Message Out to All? Health Information Sources and Ethnicity. *American Journal of Preventive Medicine*; 17(3): 198 –202.

O'Malley AS, Beaton E, Yabroff KR,Abramson R, & Mandelblatt J (2004). Patient and provider barriers to colorectal cancer screening in the primary care safety-net. *Preventive Medicine*; 39: 56– 63.

Onel E, Hamond C, Wasson JH, Berlin BB, Ely MG & Laudone VP, Tarantino AE & Albertsen PC (1998).Assessment of the feasibility and impact of shared making in prostate cancer. *Urology*;51(1): 63–66.

Pautler SE, Tan JK, Dugas GR, Pus N, Ferri M, Hardie WR & Chin JL (2001). Use of the internet for self-education by patients with prostate cancer. *Urology*; 57:230–233.

Pennbridge J, Moya R & Rodrigues L (1999). Questionnaire survey of California consumers' use and rating of sources of health care information including the internet. *Western Journal of Medicine*; 171: 302-305.

Pew Research Center: The Online Health Care Revolution: How The Web Helps Americans Take Better Care Of Themselves. http://www.pewinternet.org/reports/toc.asp?Report_26. Accessed January 9, 2003

Pinquart M & Duberstein PR (2004). Information needs and decision-making processes in older cancer patients. *Critical Reviews in Oncology/Hematology*; 51: 69–80.

Porterfield HA (1997), Perspectives on prostate cancer treatment; awareness, attitudes, and relationships. *Urology* ; 49:102-103.

Purcell GP, Wilson P & Delamothe T (2002). The quality of health information on the internet. *BMJ;* 324 (7337): 557-558.

Quirt CF, Mackillop WJ, Ginsburg AD, Sheldon L, Brundage M, Dixon P & Ginsburg L (1997). Do Doctors know their patients don't ? A survey of doctor- patient communication in lung cancer. *Lung Cancer*; 18: 1-20.

Roper Starch Worldwide Inc: American talk about science and medical news (1997) . *The National Health Council Report. Harrison, NY*

Rothenbacher D, Lutz MP & Porzsolt F (1997). Decisions in Palliative Cancer Care: Patients' Treatment Preferences for Involvement and Doctors' Knowledge About It. *European Journal of Cancer*; 33(8):1184-l 189.

Sacchetti P, Zvara P, & Plante MK (1999). The internet and patient education- resources and their reliability: focus on a select urologic topic. *Urology*; 53(6): 1117–1120.

Sainio C & Eriksson E (2003). Keeping cancer patients informed: a challenge for nursing. *European Journal of Oncology Nursing*; 7 (1): 39-49.

Satterlund MJ, McCaul KD & Sandgren AK (2003). Information Gathering Over Time by Breast Cancer Patients. *J Med Internet Res*, August, 27, 5(3), e15.

Sciamannaa CN, Clarkb MA, Diazc JA & Newton S (2003). Filling the gaps in physician communication The role of the Internet among primary care Patients. *International Journal of Medical Informatics*; 72: 1-8.

Silliman RA, Dukes KA, Sullivan LM & Kaplan SH (1998). Breast cancer care in older women:Sources of information, social support, and emotional health outcomes. *Cancer*; 83: 706–711.

Simpson M, Buckman R, Stewart M, Maguire P, Lipkin M, Novack D & Till J (1991). Doctor–patient communication: The toronto consensus statement. *British Medical Journal*;303: 1385–1387.

Singh J, Cuttler L & Silvers JB (2002). Toward understanding consumers' role in medical decisions for emerging treatments: Issues, framework and hypotheses. *Journal of Business Research*; 5763: Article in press.

Singpurwallaa N, Formanb E & Zalkind D (1999). Promoting shared health care decision making using the analytic hierarchy process. *Socio-Economic Planning Sciences*; 33: 277-299.

Steptoe A, Sutcli.e I, Coombes C (1991) Satisfaction with communication, medical knowledge and coping style in patients with metastatic cancer. *Social Science and Medicine* ;32(6): 627–632.

Stevensona FA, Barryb CA, Brittenb N, Barberc N & Bradley CP (2000). Doctor-patient communication about drugs: the evidence for shared decision making, *Social Science & Medicine*; 50: 829-840.

Szasz T, Hollender M (1956). A contribution to the philosophy of medicine: the basic models of the doctor–patient relationship. *Arch Intern Med*;97:585–92.

Takayamaa T, Yamazakia Y & Katsumata N (2001). Relationship between outpatients' perceptions of physicians' communication styles and patients' anxiety levels in a Japanese oncology setting. *Social Science & Medicine*; 53: 1335–1350.

Takayama T & Yamazaki Y (2004). How breast cancer outpatients perceive mutual participation in patient–physician interactions. *Patient Education and Counseling*; 52: 279–289.

Thorne S (1999) Communication in care: what science can and cannot teach us. *Cancer Nursing*; 22(5): 370–379.

Kleffens, Titia van; Baarsen, Berna van; & Leeuwen, Evert van (2003). The medical practice of patient autonomy and cancer treatment refusals: a patients' and physicians' perspective; *Social Science & Medicine*. Article in Press.

Truant T & Bottorff JL (1999). Decision making related to complementary therapies: a process of regaining control. *Patient Education Counseling*; 38:131–142

Vanderbilt Ingram Cancer Center (VICC). (2003). Facts at A Glance. Available at: http://www.mc.vanderbilt.edu/vicc/showcontent.php?id=14 [December 02, 2004].

Veronesi U, von Kleist K, Redmond K, Costa A, Delvaux N, Freilich G, Glaus A, Hudson T, McVie JG, Macnamara C, Meunier F, Pecorelli S, Serin D, the CAWAC Study Group (1999) Caring about women and cancer (CAWAC): a European survey of the perspectives and experiences of women with female cancers. *European Journal of Cancer*; 35(12): 1667–1675.

von Eschenbach A, Ho R, Murphy GP, Cunningham M, Lins N 1997. American Cancer Society guideline for the early detection of prostate cancer: update 1997. *CA Cancer J Clin*;47:261– 264.

Ward JA, Anderson DM, Pundik CG, Redrick A & Kaufman R (1993). Cancer Information Service utilization by selected US ethnic groups. *Journal of the National Cancer Institute Monograph*; 14: 147–156.

Winawer SJ, Fletcher RH, Miller L, et al. (1997) Colorectal cancer screening: clinical guidelines and rationale. *Gastroenterology*;112:594–642.

Wilson (2002). How to find the good and avoid the bad or ugly: a short guide to tools for rating quality of health information on the internet. *BMJ*; 324 (7337): 598- 602.

Wong F, Stewart DE, Dancey J, Mena M, McAndrews MP, Bunstony T & Cheung AM (2000). Men with prostate cancer: influence of psychological factors on informational needs and decision making. *Journal of Psychosomatic Research*; 49:13-19.

Worsley A (1989). Perceived reliability of sources of health information. *Health Education Research*; 4: 367–376.

Wyatt J (1991). Use and sources of medical knowledge. *The Lancet*; 338: 1373-76.

http://www.mc.vanderbilt.edu/irb/

http://www.mc.vanderbilt.edu/vicc/doclist.php

http://www.mc.vanderbilt.edu/vicc/showcontent.php?id=30